An exploratory study of the needs of children with life-threatening illnesses and their families and the potential role of community children's nursing.

Maynard, Linda Carole

AN EXPLORATORY STUDY OF THE NEEDS OF CHILDREN WITH LIFE-THREATENING ILLNESSES AND THEIR FAMILIES AND THE POTENTIAL ROLE OF COMMUNITY CHILDREN'S NURSING

BY

LINDA CAROLE MAYNARD

A thesis submitted for the degree of

DOCTOR OF PHILOSOPHY

UNIVERSITY OF LONDON

King's College London

Abstract

This study combined quasi-experimental and qualitative methods to explore the effects of interventions by a community children's nurse (CCN) on expressed needs of families of children with life-threatening illnesses (LTIs). Families were randomised to either intervention group (n=27) or control (n=13). Interventions occurred on 3 levels: 1) family; 2) groups of families; 3) planning and policy making. Disorder groups (DG) represented were: 1) intensive medical support (n=10); 2) progressive degenerative disorders (n=18); 3) organ failure (n=12); 4) profound disabilities (n=5). A modified Perceived Needs Scale (Quine & Pahl, 1989) categorising needs into 6 domains was used. Intervention Group participated in 3 interviews and received nurse-led interventions (over 1 year); Control Group were interviewed once. Qualitative data were obtained from tape-recorded interviews and thematic analysis occurred by cross-case display (Miles & Huberman, 1994). At recruitment Intervention Group expressed needs in all domains (mean 5.2, SD 3.8). Significantly fewer needs were expressed at Time 3 (mean 2.8, SD 1.9, p=0.03). Significant changes were demonstrated in Intervention Group mean scores concerning informational (p=<0.01), practical (p=<0.01) and social needs (p=0.02) between Times 1 and 3. Needs of Control Group were not significantly different from those of Intervention Group at Time 3, but were significantly lower than Intervention Group at recruitment (p=0.01). Qualitative analysis occurred on 3 thematic levels. Micro analysis revealed a range of expressed need and constancy of need within emotional (DG3); financial (DG2; DG3); informational (DG3; DG4); practical (DG3; DG4) and social (DG2; DG3; DG4) domains. Mezzo analysis revealed common core needs: intersectorial working; coping strategies and resources; extra help with costs of caring and practical caring; information; equipment and resources. Maps of Expressed Need and Need Zones demonstrated uniquenesses of Disorder Groups. Common factors affecting need concerned: rarity & life-threatening nature of disorder; child's functional and cognitive ability; caring interventions, coping resources; respite care; information exchange; parental participation; medical equipment. Macro analysis revealed limitations of non-categorical approach to service delivery.

Changes in Intervention Group need may have been brought about by Community Children's Nurse interventions, but contextual changes confound simple interpretation. Qualitative studies enhance understanding of experiences of families, however, controlled evaluative studies are required which attribute cause and effect before conclusions can be drawn.

Table Of Contents

	Abstract	2
	Table of Contents	4
	List of Tables	12
	List of Figures and boxes	15
	List of Appendices	16
	Acknowledgements	18
	Abbreviations	20
Chapter 1	**Introduction**	22
1.1	Background to the research	22
1.2	Context of the research	22
Chapter 2	**Literature Review**	25
2.1	Background	25
2.2	The changing health care needs of children	26
2.3	Family-centred care	27
2.4	Development of home care: an historical perspective	28
2.5	Definitions:	32
2.5.1	By diagnosis	32
2.5.2	Non-categorical approach	34
2.5.3	By type of service	36
2.5.3.1	Hospice care	36
2.5.3.2	Palliative care	39
2.6	The extent of the problem	41
2.7	Prevalence of childhood life-threatening illness	42
2.7.1	Prevalence of individual life-threatening illnesses	43
2.8	The continuing care needs of children and their families	44
2.9	Information	47
2.9.1	About the illness	47
2.9.2	At disclosure of diagnosis	49
2.9.3	Service provision	51
2.10	Equipment and resources	54
2.10.1	Medical equipment	54
2.10.2	Aids to daily living	54
2.10.3	Transportation	56
2.11	Coping strategies and resources	57

2.11.1 Caring for the child..... 59
2.11.2 Managing the situation..... 60
2.11.3 The immediate and extended family..... 65
2.11.4 Coping with the future..... 69
2.12 The additional costs of caring..... 70
2.12.1 Aids and equipment..... 72
2.12.2 Housing..... 72
2.12.3 Employment..... 73
2.12.4 Contribution of voluntary organisations..... 75
2.12.5 Guidelines for effective interventions..... 76
2.13 Practical caring..... 77
2.13.1 Respite care..... 77
2.13.2 Assistance with daily life..... 82
2.13.3 Assistance with daily treatments..... 84
2.14 Educational issues..... 85
2.14.1 Collaboration between education and health services... 85
2.14.2 Acquisition of skills..... 88
2.15 Community children's nursing..... 90
2.15.1 Introduction..... 90
2.15.2 Models of home care..... 91
2.15.3 Skills and training..... 94
2.16 Parental participation..... 95
2.17 Partnership with parents..... 96
2.18 Empowerment..... 98
2.19 Keyworkers for families..... 99
2.20 Multi-professional working..... 100
2.21 Summary..... 101
Chapter 3 Methodology..... 104
3.1 Study aims and objectives..... 104
3.1.1 Research questions..... 104
3.2 Design of the study..... 104
3.2.1 Overview of the study design..... 105
3.2.2 Development of an operational definition..... 107
3.2.3 Quasi-experimental component..... 107
3.2.4 Qualitative component..... 109
3.3 The sample..... 110

3.3.1 Process for nomination of children..... 110
3.3.2 Sample selection..... 111
3.3.3 Sample attrition..... 111
3.4 Ethical issues..... 112
3.5 Data collection: tools and measures..... 113
3.5.1 Questionnaire..... 113
3.5.2 Perceived Needs Scale..... 114
3.5.3 Coping Health Inventory for Parents (CHIP)..... 115
3.6 Data collection: process..... 116
3.7 Interventions..... 117
3.8 Strategies for analysis of data..... 117
3.8.1 Analysis of quantitative data..... 117
3.8.2 Analysis of qualitative data..... 118
3.8.2.1 Initial coding process..... 118
3.8.2.2 Analysis of 'expressed need' data..... 119
3.8.2.3 Presentation of findings..... 121
3.9 Summary..... 124
Chapter 4 The Children And Their Families And Their Context Of Care..... 126
4.1 Nomination of children..... 126
4.2 The children and their families..... 127
4.2.1 Sample attrition..... 127
4.2.2 Family interviews..... 130
4.2.3 Characteristics of children and families at recruitment... 130
4.2.4 Functional ability of the children..... 134
4.2.5 Caring interventions performed by parents..... 135
4.2.6 Expressed need for additional help..... 136
4.3 The four disorder groups..... 138
4.4 Service provision..... 139
4.4.1 Health Services..... 139
4.4.2 Social Services..... 141
4.4.3 Local Educational Authority Services..... 142
4.4.4 Voluntary organisations..... 142
4.5 Family contacts with services..... 143
4.6 Coping Health Inventory for Parents (CHIP)..... 145
4.7 Summary..... 146

Chapter 5 The Quasi-Experiment 149
5.1 Children's functional ability 149
5.2 Caring interventions performed by parents 149
5.3 Expressed need for additional help: 149
5.3.1 - Global need scores 149
5.3.2 - Need domain scores 151
5.3.3 - Constancy of Need 152
5.3.4 - Relationships between need domain scores 152
5.4 Four disorder groups comprising the intervention group 154
5.4.1 Children's functional ability 154
5.4.2 Caring interventions performed by parents 154
5.4.3 Global need scores 155
5.4.4 Differences between disorder groups 156
5.4.5 Relationships between global need scores 156
5.4.6 Relationships between global need scores by need domain 158
5.5 Nurse-led interventions 159
5.5.1 Interventions with families 160
5.5.2 Intervention projects 163
5.5.2.1 'Useful Numbers' information leaflet 163
5.5.2.2 Medical equipment loan service 163
5.5.2.3 Home-based respite care 164
5.5.2.4 Training programme for schools: food allergy and potential anaphylaxis 165
5.5.3 Strategic and operational planning 166
5.5.4 Nurse-led interventions by disorder group 167
5.6 Exploration of nurse-led interventions 168
5.7 Summary 171
Chapter 6 The Continuing Care Needs Of Families - A Micro Level Of Qualitative Analysis 175
6.1 Introduction to qualitative analysis 175
6.2 Educational need domain 176
Children:
6.2.1 - requiring intensive medical resources (DG1) 176
6.2.2 - with progressive degenerative disorders (DG2) 177
6.2.3 - with disorders resulting in organ failure (DG3) 178

6.2.4	- with profound disability (DG4).....	178
6.3	Emotional need domain.....	180
	Children:	
6.3.1	- requiring intensive medical resources (DG1).....	180
6.3.2	- with progressive degenerative disorders (DG2).....	181
6.3.3	- with organ failure (DG3).....	182
6.3.4	- with profound disability (DG4).....	184
6.4	Financial need domain.....	186
	Children:	
6.4.1	- requiring intensive medical resources (DG1).....	186
6.4.2	- with progressive degenerative disorders (DG2).....	186
6.4.3	- with organ failure (DG3).....	188
6.4.4	- with profound disability (DG4).....	189
6.5	Informational need domain.....	190
	Children:	
6.5.1	- requiring intensive medical resources (DG1).....	190
6.5.2	- with progressive degenerative disorders (DG2).....	192
6.5.3	- with organ failure (DG3).....	194
6.5.4	- with profound disability (DG4).....	195
6.6	Practical need domain.....	196
	Children:	
6.6.1	- requiring intensive medical input (DG1).....	196
6.6.2	- with progressive degenerative disorders (DG2).....	197
6.6.3	- with organ failure (DG3).....	198
6.6.4	- with profound disability (DG4).....	200
6.7	Social need domain.....	201
	Children:	
6.7.1	- requiring intensive medical resources (DG1).....	201
6.7.2	- with progressive degenerative disorders (DG2).....	202
6.7.3	- with organ failure (DG3).....	203
6.7.4	- with profound disability (DG4).....	204
6.8	Mezzo level of analysis of expressed need.....	206
6.8.1	Core themes and the creation of Need Zones.....	206
6.8.2	Development of Maps of Expressed Need.....	207
	Maps of Expressed Need: children:	

6.8.2.1 - requiring intensive medical resources (DG1)..... 207
6.8.2.2 - with progressive degenerative disorders (DG2)..... 211
6.8.2.3 - with organ failure (DG3)..... 214
6.8.2.4 - with profound disability (DG4)..... 218
6.9 Micro level of analysis of factors likely to affect the needs of families..... 221
6.9.1 Introduction..... 221
6.9.2 Children's functional ability regarding ADLs:..... 223
6.9.2.1 - Mobility..... 223
6.9.2.2 - Eating..... 224
6.9.2.3 - Eliminating..... 226
6.9.2.4 - Skin integrity / ability to turn self..... 227
6.9.2.5 - Moving and handling..... 229
6.9.2.6 - Hygiene and dressing..... 229
6.9.2.7 - Sleeping..... 231
6.9.2.8 - Communicating..... 232
6.9.3 Caring interventions performed by parents..... 234
6.9.3.1 Introduction..... 334
6.9.3.2 - Caring processes..... 235
6.9.3.3 - Interventions exceeding normal parental responsibilities..... 236
6.9.3.4 - Additional caring burden..... 240
6.9.3.5 - Additional caring burden on mother..... 241
6.9.3.6 - Parents sharing the additional caring responsibilities..... 242
6.9.3.7 - Coping with the additional demands of practical interventions..... 243
6.9.3.8 - Developing expertise with the illness..... 244
6.9.3.9 - Additional parental concerns..... 244
6.9.3.10 - Co-ordination role..... 247
6.9.3.11 - Managing the competing demands of two affected children..... 248
6.10 Summary..... 249
Chapter 7 The Continuing Care Needs Of Families - Mezzo And Macro Levels Of Qualitative Analysis..... 250
7.1 Introduction..... 250

7.2 Mezzo level of analysis of children's functional ability..... 250
7.3 Mezzo level of analysis of caring interventions performed by parents..... 252
7.4 Mezzo level of analysis of factors likely to affect need..... 254
7.4.1 Introduction..... 254
7.4.2 Identification of factors likely to affect family need..... 255
7.5 Macro level of analysis of factors likely to affect need..... 256
7.5.1 Introduction..... 256
7.5.2 Development of models for the Need Zones:..... 257
7.5.2.1 -Intersectorial Working 257
7.5.2.2 -Coping Strategies and Resources 257
7.5.2.3 -Extra Help with Costs of Caring 260
7.5.2.4 -Extra Help with Practical Caring 260
7.5.2.5 -Information..... 263
7.5.2.6 -Equipment and Resources..... 263
7.6 Macro level of analysis of expressed need within the Need Zones..... 263
7.6.1 Introduction..... 263
7.6.2 Intersectorial Working 266
7.6.3 Coping Strategies and Resources 266
7.6.4 Extra Help with Costs of Caring 266
7.6.5 Extra Help with Practical Caring..... 267
7.6.6 Information..... 267
7.6.7 Equipment and Resources..... 267
7.7 Development of Map of Family Need..... 267
7.7.1 Introduction..... 267
7.7.2 Map of Family Need: commentary..... 268
7.8 Summary..... 272
Chapter 8 Discussion..... 273
8.1 Introduction..... 273
8.2 The sample families..... 274
8.3 Quantitative findings..... 277
8.4 Micro, mezzo and macro levels of qualitative data analysis. 279
8.5 The six Need Zones..... 281
8.5.1 Intersectorial Working..... 281
8.5.2 Coping Strategies and Resources..... 286

8.5.3 Extra Help with Costs of Caring..... 293
8.5.4 Extra Help with Practical Caring..... 296
8.5.5 Information..... 301
8.5.6 Equipment and Resources..... 304
8.6 Community Children's Nursing..... 308
8.6.1 Model for community children's nursing for children with LTIs and their families: commentary..... 308
8.6.2 Professional skills..... 310
8.6.3 Professional 'inhibitors' to effective service delivery..... 313
8.6.4 Organisational 'inhibitors' to effective service delivery.... 315
8.6.5 Service elements..... 316
8.6.6 'Enablers' to effective service delivery..... 316
8.6.6.1 Family-centred care..... 317
8.6.6.2 A problem-solving approach to care..... 317
8.6.6.3 Development of a supportive partnership relationship 318
8.6.6.4 A collaborative working approach..... 319
8.7 Limitations of this study..... 320
Chapter 9 Conclusions And Areas For Further Research..... 325
Appendices..... 329
Bibliography..... 361

List of Tables

Chapter 3

Table 1 Strategy of analysis of quantitative data..... 117

Chapter 4

Table 2 Source and frequency of nominations of children..... 126

Table 3 Frequency and distribution of LTI (January 1994) n = 86..... 127

Table 4 Distribution of children by age range and gender at recruitment..... 130

Table 5 Distribution of illnesses between intervention & control groups..... 131

Table 6 Distribution of socio-economic status by father's occupation... 131

Table 7 Role of primary care giver and parental situation at recruitment..... 132

Table 8 Distribution of children by type of school attended..... 132

Table 9 Frequency of statement of special educational need..... 132

Table 10 Type of accommodation and place of residence..... 133

Table 11 Frequency of type of disability living allowance at recruitment 133

Table 12 Frequency & distribution of perceived difficulties for families at recruitment..... 133

Table 13 Frequency & distribution of extra expenditure at recruitment... 134

Table 14 Frequency of problems with functional ability at recruitment... 135

Table 15 Frequency and distribution of caring interventions performed by parents at recruitment..... 136

Table 16 Frequency and range of expressed need at recruitment..... 136

Table 17 Frequency of expressed need for additional help at recruitment..... 137

Table 18 Distribution & composition of the four disorder groups of children in intervention and control groups..... 138

Table 19 Frequency of present contacts with statutory services..... 143

Table 20 Frequency of present contacts with health related statutory services..... 143

Table 21 Frequency and distribution of present contact with members of statutory organisations..... 144

Table 22 Frequency and distribution of present contact with voluntary organisations..... 145

Table 23 Frequency of mothers' CHIP scores outside the normative range by coping pattern..... 145
Table 24 Frequency of mother's CHIP scores outside normative range and in lower third of normative range scores (i.e. family <35; support <24; medical <13) by coping pattern..... 146
Table 25 Frequency of mothers achieving CHIP scores outside the formative range by coping pattern and disorder group..... 146

Chapter 5

Table 26 Mean functional ability scores by group and interview period.. 149
Table 27 Mean caring intervention scores by group and interview period..... 149
Table 28 Mean global need scores by group and interview period..... 150
Table 29 Matched pairs analysis of the mean global need scores of intervention group families for the 3 interviews..... 150
Table 30 Frequency of expressed need for additional help with one or more items by need domain..... 151
Table 31 Intervention group Time 1 and Time 2 (matched pairs n = 26): mean need scores by domain..... 152
Table 32 Intervention group Time 1 and Time 3 (matched pairs n = 20): mean need scores by need domain..... 153
Table 33 Intervention group Time 2 and Time 3 (matched pairs n = 20): Mean need scores by domain..... 153
Table 34 Frequency of mean functional ability scores by disorder group..... 154
Table 35 Frequency of mean caring intervention scores by disorder group..... 155
Table 36 Frequency of mean global need scores by interview and disorder group..... 155
Table 37 Analysis of differences in functional ability, caring intervention and global need scores between disorder groups (Kruskal-Wallis 1-way ANOVA)..... 156
Table 38 Matched pairs analysis of mean global need scores: DG1..... 157
Table 39 Matched pairs analysis of mean global need scores: DG2..... 157
Table 40 Matched pairs analysis of mean global need scores: DG3..... 157
Table 41 Matched pairs analysis of mean global need scores: DG4..... 158
Table 42 Matched pairs analysis of mean need domain scores: DG1... 158

Table 43 Matched pairs analysis of mean need domain scores: DG2... 158
Table 44 Matched pairs analysis of mean need domain scores: DG3... 159
Table 45 Matched pairs analysis of mean need domain scores: DG4... 159
Table 46 Frequency of nurse-led interventions by activity..... 160
Table 47 Frequency of home visits by researcher by disorder group..... 168
Table 48 Nurse-led interventions and key aspects of the CCN role pertaining to the family..... 169
Table 49 Nurse led interventions and key aspects of the CCN role pertaining to multi-professional working..... 170

Chapter 6

Table 50 Creation of the six Need Zones..... 206

Chapter 7

Table 51 Thematic commonality and diversity in caring interventions among disorder groups..... 253

List of Figures and Boxes

Chapter 3

Figure 1 Quantitative and qualitative components of the study..... 106
Figure 2 Process of quasi-experimental component..... 108
Figure 3 Process of qualitative analysis of expressed need data..... 122

Chapter 4

Figure 4 Selection process and timing of quasi-experimental component..... 129
Figure 5 Service provision in locality..... 140

Chapter 6

Maps of expressed need for:
Figure 6 Children requiring intensive medical resources (DG1)..... 210
Figure 7 Children with progressive degenerative disorders (DG2)..... 213
Figure 8 Children with organ failure (DG3)..... 216
Figure 9 Children with profound disability (DG4)..... 220
Box 1 Caring interventions by parents: Higher range of abstraction.. 235

Chapter 7

Factors affecting need in the Zones for:
Box 2 Intersectorial Working 255
Box 3 Coping Strategies and Resources 255
Box 4 Extra Help with Costs of Caring 255
Box 5 Extra Help with Practical Caring 255
Box 6 Information 256
Box 7 Equipment and Resources 256

Need Zones
Figure 10 Intersectorial Working..... 258
Figure 11 Coping Strategies and Resources..... 259
Figure 12 Extra Help with Costs of Caring..... 261
Figure 13 Extra Help with Practical Caring..... 262
Figure 14 Information..... 264
Figure 15 Equipment and Resources..... 265
Figure 16 Map of Family Need..... 271
Figure 17 Model for Community Children's Nursing for children with LTIs and their families..... 309

List of Appendices

1	Inventory of LTI	329
2	Modified perceived needs scale	330
3	Functional ability scale	332
4	Semi-structured interview prompts	333
	Family expressed need by domain	
5	Educational need domain time 1	334
6	Educational need domain time 2	335
7	Educational need domain time 3	336
8	Emotional need domain time 1	337
9	Emotional need domain time 2	338
10	Emotional need domain time 3	339
11	Financial need domain time 1	340
12	Financial need domain time 2	341
13	Financial need domain time 3	342
14	Informational need domain time 1	343
15	Informational need domain time 2	345
16	Informational need domain time 3	346
17	Practical need domain time 1	347
18	Practical need domain time 2	348
19	Practical need domain time 3	349
20	Social need domain time 1	350
21	Social need domain time 2	351
22	Social need domain time 3	352
	Factors likely to affect family need:	
	Functional ability:	
23	- Mobility	353
24	- Eating and Drinking	353
25	- Eliminating	353
26	- Skin / ability to turn self	354
27	- Moving and handling	354
28	- Hygiene	354
29	- Dressing	354
30	- Sleeping	355
31	- Communicating	355

32	- Cognitive ability.....	355
	Caring Interventions:	
33	- Caring process	356
34	- Exceeding normal parenting responsibilities.....	357
35	- Additional caring burden.....	358
36	- Parents sharing the additional caring responsibilities.....	358
37	- Additional caring burden on mother.....	358
38	- Coping with additional demands of practical interventions...	359
39	- Developing expertise with the illness.....	359
40	- Managing competing demands of two affected children.....	359
41	- Additional parental concerns with caring for a child.....	360
42	- Co-ordination role.....	360

Acknowledgements

The Study was funded by the Department of Health and the Henry Smith Estates Charity.

Working with the families caring for children with life-threatening illnesses who participated in this study was a very rewarding and humbling experience. I am grateful to them for letting me into their homes and for sharing their experiences with humour, enthusiasm and honesty. Particular inspiration for this study came from a small girl, Kirsty, who was truly brave in the face of adversity and who I will always remember. I would like to acknowledge their contribution before the professionals and my family and friends – without them this work would not have been possible.

I would like to thank the members of the Homecare Project's steering committee for their advice, encouragement, help and support. Thanks are also due to the primary and secondary health care professionals, teachers and social services personnel who collaborated with this work.

Data collection and analysis were facilitated by the cooperation of many people:

- from Addenbrooke's NHS Trust: the late Sister Ginny Colliss; Mrs Penny Cook.
- from Cambridge and Huntingdon Health Commission: Dr Hilary Burton; Dr Suan Goh.
- from Lifespan Healthcare NHS Trust: Mrs Emma Baldry; Mrs Riet Noyes; Ms Ruth Palmer; Mrs Carole de Rome; Miss Abby Sykes; Dr David Vickers; Ms Eileen Woolley.
- from the Department of Community Medicine, University of Cambridge: Dr Stephen Barclay; Dr Chris Todd.
- from Royal Brompton & Harefield NHS Trust: Dr Jo Wray.
- from King's College London, University of London: Professor Alison While.

I would also like to thank some special friends who gave freely of their time and cared for my son, Henry, on numerous occasions to enable me to study and write: Elizabeth Boakes; Craig Irvine; Margaret Irvine; Chris Raby; Jane Talbot; David Vickers and Jo Wray.

I am grateful to members of my family, especially Alan, Sarinder, Patrick and Tom Day, for their continuing help and support particularly in the final stage of writing. Above all, I want to thank my parents, Peter and Val Day, as none of this would have been possible without their love and support. They have discovered at first hand that parenting continues long after children have 'grown up'.

Finally, and most specially, I want to acknowledge my son Henry, to whom I dedicate this thesis. He has shared all his life with data analysis and the writing up of this study and I need to thank him for the infinite and unconditional love which he showers on me, his Mummy, every day. His extraordinary smile and lively chat are constant reminders of the preciousness of life and good health.

Abbreviations

ACT	Association for Children with Terminal and Life-threatening Conditions and their Families
ADLs	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
CCN	Community Children's Nurse \ Nursing
CF	Cystic Fibrosis
CHD	Congenital Heart Disease
CHIP	Coping Health Inventory for Parents
CMO	Clinical Medical Officer
DG	Disorder Group
DGH	District General Hospital
DLA	Disability Living Allowance
DN	District Nurse
GP	General Practitioner
HIV	Human Immunodeficency Virus
HV	Health Visitor
ICD9	International Classification of Diseases (9^{th} edition)
LEA	Local Education Authority
LSA	Learning Support Assistant
LT	Life-threatening
LTI	Life-threatening Illness
MPS	Mucopolysaccharide disorders
NAHA	National Association of Health Authorities
OPCS	Office of Population Census and Surveys
PHCT	Primary Health Care Team

QSR NUD*IST	Qualitative Solutions & Research Pty Ltd. Non-numerical Unstructured Data: Indexing, Searching & Theorizing
RCN	Royal College of Nursing
RCPCH	Royal College of Paediatrics and Child Health
SIDS	Sudden Infant Death Syndrome
SN	School Nurse
SSD	Social Services Department
WHO	World Health Organisation
WTE	Whole Time Equivalent

Chapter 1 Introduction

1.1 Background to the research

Children have distinct and significantly different needs from adults and the provision of effective health, social and educational services for children is dependent upon a comprehensive understanding of these special needs (Department of Health, 1997). These special needs were recognised by the Department of Health's (NHS Executive, 1998) funding initiative of a series of pilot projects into the study and discovery of services for children with life-threatening illnesses (LTIs), and the 1997 working party composed of members of the Association of Children with Terminal and Life-threatening Conditions and their families (ACT) and Royal College of Paediatrics and Child Health (ACT & RCPCH, 1997). The findings of both these initiatives recommended that community children's nursing (CCN) should be available to all such children.

The House of Commons Health Committee (House of Commons, 1997) advocated that children's health services must have children as their focal point and be needs-led rather than based on traditional patterns of service delivery. Evidence presented to this Committee unfortunately pointed to the contrary, revealing that health services for sick and disabled children did not always take the specific needs of children and their families into consideration. The committee received evidence which stated that children with LT and chronic illnesses had un-met needs concerning: community children's nursing, the provision of aids and equipment and respite care. Accordingly it recommended that considerable improvements in services were required and that the needs of this group of children and their families should receive urgent attention.

1.2 Context of the research

This research arose from one of the pilot projects funded by the Department of Health to help families caring for children with LTIs (NHS Executive, 1998).

The initiative was announced in January 1992 by the then Secretary of State for Health who proposed: "We want to define the needs of such children more specifically so that we can publicise good practice on the organisation, management and funding of services to meet those needs" (Department of Health, press release 1992). The researcher was a children's nurse specialist appointed to co-ordinate the project, undertake research with families and pilot a community-based, community children's nursing (CCN) service. She was supported in the various aspects of her role by a multi-professional steering committee which met quarterly and included representatives from statutory and voluntary services providing care for children and their families in the locality. Academic support was received from the Health Services Research Group within the Department of Community Medicine at the University of Cambridge. From a nursing perspective, additional support on a daily basis was provided with the appointment of a community children's nursing sister by the local community NHS Trust six months after the commencement of the study.

A review of the literature, at the beginning of the study in 1993, revealed a paucity of robust research pertaining to the needs of children with LTIs and their families. While there was a wealth of anecdotal evidence pertaining to family need, few research studies had been conducted which explored the needs of this group as a whole. A few early studies were available (e.g. Burton, 1975) and others were beginning to emerge which focused on particular disease groups such as cancer, disability and liver disease (e.g. Baldwin, 1985; Quine & Pahl, 1989; Goldman et al, 1990; Sloper & Turner, 1991; Bradford, 1991). However, the literature was clear in noting that technological, pharmaceutical and surgical advances had enhanced the life expectancy of children with LTIs, and in this way their continuing care needs are greater now than ever before thus warranting consideration and research. Additionally, the lack of controlled or evaluative research studies reported in the literature pertaining to the activities of community children's nurses or relating to their mode of service delivery were conspicuous by their absence, and thus contributed to the design of the study as the need for such research was highlighted. The series of LTI pilot projects (NHS Executive,

1998) generated some literature although few were designated research projects. Nevertheless, dissemination of findings is an important aspect of any new mode of service delivery, despite the fact that time constraints and other responsibilities to the organisation often preclude this. Importantly, this situation is currently changing in light of recent government publications (NHS Executive, 1996; Department of Health 1997; House of Commons, 1997; NHS Executive, 1998).

The design of the study was therefore, out of necessity, exploratory in nature and not without difficulty. The lack of a concrete definition for childhood LTI as the study commenced created additional methodological problems. The opportunity to pilot nurse-led interventions for children and their families in their own homes contributed to the decision to examine the effectiveness of such interventions in a small scale quasi-experiment.

The researcher, has considerable experience as a children's nurse working with families of children with LTIs. A particular strength of this study lies with the researcher's prior understanding of the needs of families and her ability to use these nursing skills to quickly establish a rapport with families recruited to the study. The decision to perform a series of semi-structured interviews with a randomly selected group of families who received nurse-led interventions in response to their needs, enabled a rich and unique data-set to be obtained. This might otherwise have been missed had a single interview with families been performed by a researcher who did not have prior knowledge or experience. This created an appropriate environment to explore the potential role of community children's nursing for children with LTIs. This study confirms the findings of earlier studies and enhances our understanding of the service needs of children with LTIs and their families. More importantly, however, it contributes to a burgeoning body of literature pertaining to community children's nursing services which should be available for all sick and disabled children being cared for at home by their families. The model proposed should be of particular interest to the recently formed Diana Nursing Teams who have a specialist role with children with LTIs and their families.

Chapter 2 Literature Review

2.1 Background

Fortunately, death in childhood from life-threatening illness (LTI) is rare (Goldman, 1994). Nevertheless, a small but significant number of families face the unenviable possibility that their child will die from some form of LTI in childhood or early adulthood (NAHA, 1988). It is now commonplace for such families to manage the complexities of their child's care within the confines of their own home (While et al, 1996a; House of Commons, 1997; Kirk, 1998).

A diagnosis of LTI in childhood is a major crisis for a family (Davis, 1993). It revolutionises family life and has a profound effect on all family members particularly those involved in the day to day care of the child (Burton, 1975; Dominica, 1990a; Stein et al, 1989; While et al, 1996a). Few families at disclosure of diagnosis realise the extent to which every aspect of their lives will change (Eiser, 1990). Family values, plans and expectations undergo radical adjustment and a period of anticipatory mourning is initiated (Burton, 1975; Baum, 1994). The consequent emotional and physical distress for parents caring for children with such illnesses is likely to be considerable and long-lasting. The daily burden of care, coexisting with the threat of death, day after day, week after week, and often year after year, invariably falls on the family (Perrin, 1985). However, for these families, in contrast to those whose children die suddenly from accidents or acute illness, care plans can be made for the mobilisation of appropriate services (NAHA, 1988).

Compared with even one generation ago fewer families in the Western world now experience childhood mortality. Consequently there is a smaller group of families and professionals with the relevant experience to support those whose children die or who are living with a LTI (Baum, 1990). The perceived curative powers of enhanced technological and scientific medical advances coupled with the expectations of good health may, in fact, serve to exacerbate the heartache of those families who do lose their children (Baum, 1994). Caring for children with LTIs and their families can, therefore,

generate considerable anxieties for professionals in all organisations caring for such children (Stein & Woolley, 1994).

Thus, a clear understanding of the needs of families caring for children with LTIs is essential for professionals (Sloper & Turner, 1992). Not only to ensure that families receive appropriate and effective support pertinent to their requirements but also to identify the short falls in service provision. The burden experienced by families in their caring role is likely to be positively influenced by professionals who demonstrate an understanding and are responsive to family need (Baine et al, 1995). Over the last decade there has been a growing awareness among professionals and voluntary groups that large deficits exist in the provision of care for families caring for children with LTIs (Baum, 1990). This is because a wide spectrum of services across the health, social services and education sectors need to be available and accessible to meet the individual needs of families which change over time (ACT & RCPCH, 1997).

2.2 The changing health care needs of children

A fundamental aspect of childhood is a child's continuous physical, emotional and cognitive development. An increase in understanding of the emotional vulnerability of the young child and the effect which experiences in early life can have on later development (Bowlby, 1953) has influenced all aspects of caring practices for the sick child. The changing health care needs of sick and disabled children have also contributed to the rapid development of services. In addition, the transformation in the approach to the care of children coupled with the shift in emphasis from hospital to home care has led to innovation and refinement of community services (House of Commons, 1997).

Technological, pharmaceutical and surgical advances have enhanced the life-expectancy of children with conditions such as cystic fibrosis (CF) (Whitehead et al, 1991; Maynard, 1993) and cardiac abnormalities (Joffe & Vergoda, 1990). Childhood cancer is increasingly curable (Stiller, 1994)

although the burden upon families is great as they often face lengthy hospitalisation and complex treatment regimens (Henderson et al, 1992). Improvements in neonatal intensive care have contributed to the increase in survival of babies of very low birth weights so that although the risk of complications is falling, more are surviving birth. As a consequence there is an increase in the number of babies and children with long term health care needs (Roberton, 1993). Evidence from the national study of health and growth (1973-1986) suggested that the prevalence of asthma in childhood is increasing (Burney et al, 1990). Both Childs and Dezateux (1991) and Bendefy (1991) noted that the use of nebulisers at home is now popular but that families have a need for better instruction and supervision. These advances have contributed to the emergence of a group of chronically ill children who are dependent upon technology for their survival (Kirk, 1998). Forty three percent of the disabled children less than two years of age in Beresford's (1995) study were dependent upon some form of medical technology.

2.3 Family-centred care

It is now widely accepted that family-centred care is fundamental to the provision of care for sick and disabled children (Jolly, 1981; Department of Health, 1991; Stower, 1992; Nethercott, 1993; Whyte, 1992) whether care is provided in hospital or at home. This philosophy centres firmly on the recognition of the child as a member of a family and views the family as a dynamic system. The focus is on the needs of all members not just on the individual for whom care is required and with individual family members interacting within the whole (Sciarrillo, 1980; Wise, 1994). Complete ease of access to the child by his / her parents or other members of the family is a major principle of the provision of hospital services. This is not a luxury but a fundamental standard to be adhered to in the care and treatment of all sick and disabled children (Department of Health, 1991). This guiding principle assists in the education of the family in both the clinical condition affecting the child and in domains such as parenting and health promotion. Furthermore, it enables parents to play an active role in the care of their child

and to continue this care following discharge home. Childhood LTI causes disruption to all family relationships and to each individual family members' way of life (Van Dongen - Melman & Sanders - Woudstra, 1986), therefore, it is appropriate that 'the family' as a whole is the unit of care (Peace et al, 1992; Wise, 1994). In a 'family equals home' analogy Wise (1994) argued that home is where the family is and therefore where the child should be. Thus, the sick or disabled child should remain within the home environment if at all possible surrounded by his / her family. Inclusion of health professionals into this analogy suggests that they should be going to the child rather than vice versa (Wise, 1994).

2.4 Development of home care: an historical perspective

The need to provide care for children outside hospital has long been advocated. While (1991) has succinctly outlined British government policy relating to community care services for children since the inception of the National Health Service (NHS). The report of the committee chaired by Platt (Ministry of Health, 1959) emphasised the deleterious psychological effects of hospital care, revealed by Bowlby (1953), and recommended that the child and mother should not be separated and that admission to hospital should only occur if appropriate care could not be provided in the community. Further, it advocated that home nursing schemes should be developed to meet this recommendation. This committee gave rise to the National Association for the Welfare of Children in Hospital (NAWCH now known as Action for Sick Children) which pioneered the way forward in recognition of the benefits of involving parents and carers in the health care and treatment of their children. The Court Report (Department of Health & Social Security, 1976) placed greater emphasis upon home care than earlier government documents and recognised a need for an integrated approach to children's health services in as much as it considered the child as a continuously developing individual within a family system. It also highlighted the fact that the recommendations made 19 years earlier had not been implemented and a rapid expansion of paediatric home care schemes was again advocated.

Evidence elicited by the working party which produced the document Care of Dying Children and their Families (NAHA, 1988), emphasised the home as the principal care setting for children, with adequate and appropriate support to enable parents to care successfully for their child if they so wished. A view reiterated in government guidance in 1991 which emphasised not only the paramount importance of maintaining a child's attachment with his family and home, but also the essential links required between hospital and other NHS primary and community services to promote a "seamless web" of care. Further it recommended as one of its cardinal principles that: "children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital" (Department of Health, 1991 p. 2). In addition, in accordance with previous policy directives it recognised the contribution of community children's nurses in providing support to families at home in conjunction with GP's and hospital personnel. Recommendations from this report were incorporated into the Patient's Charter, (Department of Health, 1996) which offered expectations for families including, care at home whenever possible and with accompanying appropriate support.

The 1996 guidelines for good practice (NHS Executive, 1996) complemented the earlier guidelines (Department of Health, 1991) by outlining those child health needs which can best be met outside hospital. They endorsed the principles for good quality care for children with LTIs identified by the Association for Children with life-threatening and Terminal illnesses and their families (ACT) in their Charter (ACT, 1993). In particular, the acknowledgement of the parental role as one of primary carer was emphasised. In addition, the importance of respite care and support in the home and following bereavement was reinforced. The guidelines considered that collaboration between voluntary organisations, health purchasers, providers and other statutory services was essential for a comprehensive, high quality and cost effective service for these families (NHS Executive, 1996).

The plight of families caring for children with LTIs was recognised with the £5

million initiative funded by the Department of Health in 1992. The Secretary of State announced: "we want to define the needs of such children more specifically so that we can publicise good practice on the organisation, management and funding of services to meet those needs" (Department of Health, 1992 press release). While the work of the children's hospice movement was valued the intention was to see respite, home support and residential care services developed further in the range of health and social services for children. The evaluation of the pilot projects (NHS Executive, 1998) synthesised the main findings from the evidence of the 52 projects and among the major conclusions was the recognition that "a children's community nursing service made a vast difference to the care of families" (p. 34). A comprehensive guide to the development of children's palliative care services ensued from working party evidence (ACT & RCPCH, 1997) and included information on an overview of the current national situation as well as principles for the purchasing and providing of services

Despite the slow evolutionary development of community children's nursing, evidence shows that complex nursing care, involving highly technical procedures, has been and is being carried out in the home environment, frequently by parents (While et al, 1996a; Kirk, 1998). The provision of services to meet this need is gradually gaining momentum with the development of community children's nursing services throughout the country to provide more care for children and their families at home (Whiting, 1988; Lessing & Tatman, 1991; Tatman & Woodroffe, 1993, While & Dyson, In press). The initiative of the Princess Diana Memorial Committee has added impetus to the continued increase in provision (NHS Executive HS circular, 1998), and the focus of this study lies specifically with the population of children and their families to be served by the Diana Nurses. The Audit Commission's (1993) survey of 48 families caring for children with chronic illnesses showed that the presence of home care nursing can reduce the amount of time some children need to stay in hospital as well as reduce the number of unnecessary hospital admissions. A considerable investment of financial and management resources are necessary with the inception of a children's community nursing team (RCN, 1993a; RCN 1994). However, it

has been suggested that such teams could be funded through hospital savings with the reduction in the overlap of nursing shifts, by re-allocating clerical and house keeping tasks to non-nursing staff and with the flattening of the nursing management hierarchy (Audit Commission, 1993).

While (1991) proposed that paediatric home care as an alternative to hospitalisation is advantageous for a number of reasons. Importantly children experience less emotional trauma and decreased anxiety as do their families. Evidence has suggested that maintaining family unity is an important aspect in reducing anxiety (e.g. Cleary et al, 1986). Further, it allows parents to remain in control and manage their child's illness in an environment in which they feel comfortable (Goldman & Baum, 1994). While anxiety levels may be high in the first instance, research has shown that parents are less anxious when they care for their child themselves (Edwardson, 1983; Andrews & Nielson, 1988). When hospitalisation is unavoidable the presence of a home care scheme can facilitate early discharge (Oppe, 1971; Atwell & Gow, 1985; Audit Commission, 1993) and reduce the duration of hospital stay (Lightwood et al, 1957; Hally et al, 1977; Jennings, 1994).

Home care may be a more effective use of resources (While, 1991). Evidence has demonstrated that parents have considerable out goings when their child receives treatment in hospital (Beresford, 1994), although later studies have also demonstrated that home care also has financial implications for parents (Smyth & Robus, 1989). Forty-two of the families (n=99) in While et al's (1996a) study were reported to be just managing financially. Early research indicated that care for children at home would have substantial benefits to health authorities in that hospital beds would be released with the consequential decrease in waiting list times (Lightwood et al, 1957; Oppe, 1971; Hally et al, 1977). This assumption is further highlighted by Atwell and Gow (1985) who drew attention to the enormous cost difference between a one day stay in hospital and a visit from a paediatric community sister. Further evidence regarding comparative costings presented to the House of Commons Health Committee (1997) by North Hampshire Loddon Community NHS Trust showed substantial

differences. For example, the total cost of care for a child with CF over a six month period was more than halved (£7,100 versus £3,060) due to the presence of a CCN service able to support the child and family at home. Complex care packages for children invariably involve care from more than one source and generally take place in different locations thus making it difficult to evaluate services from an economic perspective (Goddard, 1991). It is essential to include a comparative cost analysis (While et al, 1996a) when evaluating the provision and quality of services to discover the true costs for both the family and for statutory and voluntary services because high quality community care is not cheap (Dominica, 1982; Neale, 1990). Savings to health care providers may not be substantial thus the assumption of home care as a cheaper option is questionable (Editorial At Home, 1994).

The potential benefits of home care such as continuity of care (NAHA, 1988) and increased parental control (Goldman & Baum, 1994) may be outweighed by the psychosocial costs borne by families (Kirk, 1998). For example, the dilemma of needing professional support but also their own privacy as their daily lives are often dominated and revolve around procedures related to their child's need for care and dependence on technology. Indeed, the Audit Commission (1993) cautioned that care must be taken to avoid families incurring an intolerable burden of care when the principal caring role lies with the family.

2.5 Definitions

2.5.1 Definitions by diagnosis

Illnesses vary in stability - two conditions with different courses may seem equally severe on any single assessment (Stein et al, 1989). A view supported by Tatman (1993) who argued that in practice childhood LTI is not comprised of a rigid set of medical diagnoses. Definitions are often determined as much by the severity of the disease as by the diagnosis itself necessitating continuous or sequential assessment to gain a true picture of a child's functional status and the illness burden faced by the family over time.

However, While et al (1996a) utilised a comprehensive list of diagnoses based on the 9th revision of the International Classification of Diseases (ICD 9 codes) (WHO, 1975) which could serve as a guideline for their research criteria. The determining factor for a definition of LTI appears to be whether or not an illness may cause a serious threat to a child's life (Sutherland et al, 1993). Many children suffer with some form of chronic illness which may affect them for extended periods of time, often for life, and may not be amenable to cure, but which is unlikely to predispose to early death (Eiser, 1990). Conversely, LTIs, such as cancer and diseases associated with irreversible organ failure, may or may not be curable but will lead to premature mortality if treatments are unsuccessful (Chambers, 1987; Sutherland et al, 1993). While the progressive, degenerative trajectories of life-limiting incurable disorders suggest that death may be anticipated in childhood or early adulthood (Chambers, 1987; Burne, 1994; While et al, 1996a).

In 1996 a Working Party convened to consider the provision of children's palliative care services in the UK and received evidence from more than 70 individuals representing a wide range of disciplines including parent groups, hospices and paediatric services (ACT & RCPCH, 1997). In proposing a definition for children's palliative care they offered a classification for LTIs delineating four broad groups:

1) LTIs for which curative treatment may be feasible but can fail. They cited cancer and irreversible organ failures as examples.

2) Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities but where premature death is still possible, as with, for example, conditions such as CF and muscular dystrophy.

3) Progressive conditions for which there are no curative treatment options and where treatment and care is exclusively palliative and may extend into adolescence or early adulthood. They cited the mucopolysaccharidoses as examples in this group.

4) Conditions with severe neurological disability which confer susceptibility to health complications and may deteriorate unpredictably but are not generally considered to be progressive, for example, severe cerebral palsy and brain and spinal cord injuries resulting in multiple disabilities.

The inclusion of muscular dystrophy in the second group may have been a typographical error since disorders "like Duchenne's muscular dystrophy develop and progress through childhood, with death as an adolescent anticipated. ...Since none of these diseases can be cured, care for the children is palliative from the time of diagnosis" (Burne, 1994 p. 25). Goldman (1998) cited CF, HIV infection and AIDS as examples of conditions for such a group in her more recent delineation of definitions.

2.5.2 Non-categorical approach

In 1975 Burton argued that parents of children with CF resembled parents of children suffering with other incurable illnesses such as some forms of cancer and leukaemia. She concluded that while the outlook for children was continually improving, such diseases were potentially fatal and required similar family adaptation. More than 20 years later, working party evidence (ACT & RCPCH, 1997) demonstrated a similar view in proposing that the common factor to be reflected upon in the care of children with LTIs was the likelihood of death in childhood or early adulthood necessitating the production of care plans to meet their individual and family needs.

The use of the term LTI to encompass all these conditions where premature mortality may be expected enables the use of a non-categorical approach to identify the needs of affected families (While et al, 1996a). This approach, proposed by Stein and Jessop (1982) focuses upon the common characteristics of the children and families studied rather than problems specific to the disease process. Children and their families may face many more similarities than differences and that the nature of the family may be more likely to determine the frequency and types of problems experienced rather than the distinct nature of the illness. Thus, the need for interaction

with a large number of care professionals, uncertainties about the prognosis and increases in stress related to the demands of caring interventions are factors considered common to all families (Eiser, 1993).

The interaction between individual risk and resilience factors which influence child and family adaptation to chronic illness has been explored by Wallender et al (1989a; 1989b). Supporting a non-categorical approach they argued that their model of child and maternal adaptation to chronic conditions, (considered worthy of reproduction by both Eiser (1990; 1993) and Bradford (1997)), was applicable to any disorder in childhood and should therefore be a useful tool when studying the effects of chronic illness. In Bradford's (1997) review of Wallander et al's (1989a) work he suggested that this model, as a theoretical framework, was the "most sophisticated and coherent" (p. 146) to be reported in the literature so far. For this reason he offered a critique of the research studies carried out by Wallander et al (1989a) to test their model. In conclusion, Bradford (1997) noted that, the model was both unique in its ability to specify the relationship between factors and in its predictive powers for identifying those who are at risk of poor coping. Nevertheless, there was, he deduced, a need to modify the framework to strengthen its validity as some of its predictions received only tentative support or were not substantiated.

Both Eiser (1993) and Bradford (1997) critiqued the psychological literature for the advantages and disadvantages of a non-categorical versus a disease orientated approach to research with families. Eiser (1993) asserted that it was not possible to distinguish between the benefits of the non-categorical approach and one which maintained that specific diseases have unique qualities requiring distinct research protocols and clinical interventions. The majority of published research reviewed by Eiser (1993) pertained to a handful of conditions only, particularly cancer, diabetes, spina bifida and CF; and that most studies were non comparative and limited to the consequences of one condition.

2.5.3 Definition by type of service

2.5.3.1 Hospice care

One method of estimating the prevalence of children with LTIs is to consider the pattern of usage of children's hospices (Baum, 1994). The degree of utilisation of these establishments for respite, palliative and terminal care and bereavement support (Millar, 1990; Dominica & Hunt, 1993; Goldman & Baum, 1994; Hill, 1994; Farrell, 1996; Davies, 1998; Robinson & Jackson, 1999) emphasises that many families have a need for this type of service. However, the use of this method, pre-supposes that all professionals caring for children with LTIs have knowledge of available facilities and services provided by such establishments in order to refer families. In the directory of services outside hospital for children with LTIs, Tatman (1993) identified five children's hospices in the UK and Hill (1994) commented that these were finding it difficult to meet the demands for care. Presently there are 15 hospices (Thompson, 1998) with several more in the planning stage (ACT & RCPCH, 1997) but unfortunately their distribution is not related to the population (Davies, 1998). Local scale planning by charitable organisations has meant that some areas are without a service. The lack of a strategic national perspective has resulted in some children and families having to travel long distances to receive the benefits of hospice care (Dominica & Hunt, 1993; Soutter et al, 1994). If the usage of the five hospices in 1994 (Baum, 1994; Hill, 1994) offered an indication of the national burden in supporting families with children with LTIs, the fact that numbers of establishments have tripled in the last five years can serve only to highlight the inadequacy of past services and the underestimates of the numbers of children involved. This, therefore may not be a reliable method of estimating the prevalence of children with LTI. Although, with hindsight, it is clear that in 1994 there was a lack of factual evidence both locally and nationally to demonstrate the extent of family need (Davies, 1998).

There has been a certain amount of controversy surrounding the growth of the children's hospice movement (Burne, 1982; Chambers, 1987; Broadbent,

1987). Mother Frances Dominica herself (the founder of the first children's hospice in the UK - Helen House) remarked back in 1987 that 3 or 4 children's hospices around the UK would meet present demand. The symposium cited by Chambers (1987) convened to debate the need for a children's hospice movement similar to that for adults appeared to support Dominica's view in that no more than four children's hospices would be needed in Britain. Correspondence in medical journals (Anon, 1983) challenged the necessity of children's hospices wondering instead whether they were a "fashionable indulgence", and arguing that institutional arrangements were second best to the care of families in their own homes. Soutter et al's (1993) study was designed to explore whether an alternative to hospice care could provide the same level of support to families. In their interviews with families (n=31) they revealed the need for respite care out of the hospital environment and that it should be for the whole family with appropriate nursing care available for the sick child. Further, they proposed that it should not be part of an adult facility but be a small self-contained unit which was just one component of a comprehensive service to families (Soutter et al, 1994).

Why then has there been such an upsurge in the growth of the children's hospice movement? Broadbent (1987) suggested that this has been due to the general public's preference to put money into bricks and mortar rather than supporting the hospice philosophy in a more "visionary and thoughtful" way. Goddard (1990) concurred and proposed that it arose from an emotion driven response rather than one resulting from a systematic evaluation of need. In the first exercise in health service priorities based on a random sample of the British population the highest priority was for the treatment for children with LTIs followed by special care and pain relief for people who are dying (Bowling, 1996).

There has been some confusion with the perceived function of children's hospices in that some have equated them with having a similar role to adult hospices and are therefore places where children go to die (Davies, 1998). Although Farrell (1996) noted a commonality between adult and children's

hospices in that both organisations had 'advanced the boundaries of quality care'. Further empirical research is required to identify the true benefits of hospice care in comparison with other forms of care, for example, with home care. Indeed, some hospices have recognised the need for outreach nursing (Day, 1990; Rigg, 1996 personal communication). Children's hospices may play a special role in terminal care, offering privacy, continuity of care and ample time in circumstances where death at home is not desired or possible (Stein & Woolley, 1990), thus leaving the home untainted by death. Other research, however, has shown that the majority of admissions to children's hospices are for respite care (Soutter et al, 1994; Stein et al, 1989; Dominica, 1987; Stein & Woolley 1990; While et al, 1996a). The principal locations for respite care for families (n= 40) in While et al's (1996a) study were residential care and hospices. Further, of those identifying a preferred type of respite care respondents (n=99) most frequently reported their own home or a hospice as the places in which they would most like to have respite care for their child.

It is unlikely that the "gold standard" of care provided by children's hospices could ever be totally matched by publicly funded organisations such as social services or the NHS (Davies, 1998). The fact that all are provided by the voluntary sector highlights the heavy dependence on the voluntary sector for many aspects of care for children with LTIs (ACT & RCPCH, 1997). Further, it may also suggest a certain degree of complacency on behalf of the statutory services in recognising their responsibility towards the respite care needs of children and their families. Nevertheless, there are alternative modes of service provision. 'Hospice' is a philosophy rather than a facility with the approach to care being more important than the building in which caring takes place, and can be put into practice wherever there is a child with an illness which poses a threat to life (Dominica, 1990a).

Children's hospices may be chosen by parents as a facility for respite care because of the range of options which are available to them. It may be difficult for other respite services (e.g. social services residential care) to match the quality of care and facilities offered as the majority of hospices

have been purpose built to an individual style (Davies, 1998). Size and furnishings are designed to create a "home from home" environment (Hill, 1994) and offer a very high ratio of nursing staff to clients (Dominica and Hunt, 1993; Davies, 1998). A range of facilities have been described, such as: sensory light room (Farrell, 1996); hydrotherapy pool (Millar, 1990; Davies, 1998) well equipped kitchen with individualised menus and an opportunity for children to do home baking (Hill, 1994), jacuzzi (Herd, 1990); accommodation for pets (Hill, 1994); quiet and peaceful gardens and outside play areas (Herd, 1990; Davies, 1998).

In her review of the growth of children's hospices, Davies (1998) reiterated that it is not just the calibre of their facilities which enables them to provide quality care for children with LTIs and their families. It is the underlying ethos of their philosophies of care offering friendship and support to the whole family which promotes their excellence. Farrell (1996) suggested that a truly family-centred approach within an environment dedicated to the specific needs of sick and disabled children "advances the boundaries" of quality care for children and their families. Furthermore he proposed that hospice care is, without doubt, a unique model of care offering families another choice to assist them in their caring role. With a number of hospices in the planning stage Davies (1998) asserted that while the children's hospice movement may be a late 20th century phenomenon it looks set to continue into the millennium and beyond. Nevertheless, the palliative care expertise developed within the children's hospice organisation should be shared. Such facilities should not be viewed in isolation but be complementary to other caring services.

2.5.3.2 Palliative care

An alternative method of estimating the number of children living with LTIs is to determine those children receiving palliative care. However, this is an unrecognised and under-developed area of care and the need for palliative care for children with LTIs and their families has only recently been considered a speciality in paediatrics (Goldman, 1998). The development of

the most suitable approaches to children's palliative care are still in their infancy and the provision of services on a national scale are sporadic and frequently inadequate (Goldman, 1998). Therefore, to try and determine the extent of the problem by recording those children receiving palliative care is unlikely to produce an accurate or useful figure. There may be difficulties in distinguishing between aggressive treatments to cure or prolonging a good quality of life and palliative care, as the transition between the two modes of care is not always clear cut. There may be a gradual shift from curative to palliative treatment or both approaches may be used in tandem, each becoming dominant at different times; while in other instances care may be palliative from diagnosis (ACT & RCPCH, 1997).

Palliative care is an active and total approach to care which encompasses the physical, emotional, social and spiritual needs of children and their families and has at its heart the quality of life of the child and support for the family. It includes several facets of care such as the management of distressing symptoms, provision of respite care, terminal care and support into the bereavement period and beyond (ACT & RCPCH, 1997). Parents are part of the team caring for the ill child but also part of the family in need of care themselves. As principal carers, parents should be included fully in the care team, and be provided with information, able to negotiate plans of care, taught appropriate caring skills and be assured that advice and support is accessible 24 hours a day (Goldman, 1998). This model is the gold standard to which all services should aspire and has been developed on a comprehensive basis for children with cancer (Stevens & Owen, 1987). Sadly, models of service for children with non-malignant disease are less coordinated and sporadic (Goldman & Baum, 1994), although where a locally based service has been developed this is proving to be valuable (Wallace & Jackson, 1995). As this appears to be the exception rather than the rule it may be impossible to identify those children currently in receipt of, or more importantly, in need of palliative care in a locality from a source such as a District database. For this method to be an accurate one in identifying the numbers of children and families involved there is a need for both a managerial and clinical focus (ACT & RCPCH, 1997).

2.6 The extent of the problem

Approximately 1,100 children die from LTIs in England and Wales per annum (While et al, 1996a). Local small scale studies (Duncan & O'Flynn, 1995, Maynard et al, 1996) have found that between a quarter and one third of childhood deaths each year were due to some form of LTI. Although, extrapolation of data from extremely small sample sizes, such as in these studies, may produce figures associated with wide 95% confidence intervals, thus generalisation of findings from small scale projects are unlikely to be robust. Nevertheless, findings from these studies were similar to the national perspective offered by While et al (1996a).

Thornes (NAHA, 1988) reported that 1600 deaths from LTI occurred in children (age range 0-16 years) in 1986. She estimated this to be 15% of the total number of childhood deaths occurring in the UK during that year. Baum (1994) cited 1990 figures for causes of death (age range 1 to 14 years) in England and Wales (OPCS, 1990). Accidents, poisoning and infections accounted for 37% of deaths while malignancies and other deaths accounted for the major proportion (63%) of the total number of deaths. Deaths in the peri-natal period are excluded by the use of the 1 - 14 year age range as are deaths from LTI which occur during the first year of life and the adolescent period. While et al (1996a) used a different methodology. Their comprehensive analysis involved mortality data between 1987 to 1991 for children aged 1 to 17 years resident in England and Wales. Mortality rates by Regional Health Authority and age range were presented: while figures for the 18 to 19 year age group were offered the mortality of infants aged below one year did not form part of their study. From their investigation they proposed that the incidence of deaths in England and Wales from life-limiting incurable disorders was 10.3 : 100,000 for children aged 1 to 17 years.

The differing figures presented above offer a confusing global picture concerning the extent of the problem. Bradford (1997) noted reasons for discrepancies in research into the prevalence of chronic childhood disorders, and such inconsistencies can apply when considering the epidemiology of

LTI. The operational definitions used to characterise LTI can significantly affect the number of children subsequently identified. In addition, research methodology, for example, the use of questionnaires compared with interviews or with the analysis of national statistics versus local data, can contribute towards producing differing sample attributes and hence different results.

2.7 Prevalence of childhood life-threatening illness

Both Eiser (1993) and Bradford (1997) reported evidence from the North American literature in concluding that 10-15% of children aged under 16 years were affected by chronic long term conditions (Gortmaker, 1985). In addition, 10% of children who were chronically ill have been reported to have a severe chronic illness (Perrin, 1985).

Attempts have been made to estimate the prevalence of children living with LTI in the UK (NAHA, 1988; Baum, 1994; While et al, 1996a). Accurate estimation has proved impossible due to the lack of comprehensive morbidity databases at both national and local level (While et al, 1996a) and the large number of rare conditions encompassed within the operational definition of LTI. Thornes (NAHA, 1988) estimated that 5400 children would be living with a LTI in any one year in the UK. She used this figure to calculate that an average English health authority with a population of 54,500 children aged between 0 and 16 years might expect 26 children to be living with LTI in any one year. Baum (1994) disputed this figure proposing instead a national figure of 20,000 children although the basis for this figure was not given. While et al (1996a) concluded that morbidity data made available to their study was suspect and likely to reflect the inconsistent way in which data were recorded prior to the introduction of NHS reforms as a consequence of the NHS and Community care Act (1990). In the absence of robust morbidity data bases they postulated that it was impossible to make any firm estimate regarding the number of children living with life-limiting incurable disorders.

2.7.1 Prevalence of individual life-threatening illnesses

Among individual LTIs the best data are for children aged 0-14 with cancer as there is a system of national registration in place which covers the whole of the UK (Stiller et al, 1995). Two thirds of the 11,479 children on the register were likely to survive for 5 years or more (Stiller, 1994) although the register does not give data regarding the health status of surviving children. In 1986, 1,482 children and young people (0-18 years) were newly diagnosed with cancer, a rate of 1.1 per 10,000 (Draper, 1995).

There are national databases for three degenerative conditions. The population of children and young people under 18 years of age with CF presently remains stable with 4,500 children known to be living with the disorder (Botting, 1995); which represents a prevalence rate of 3.9 per 10,000. Green and Murton (1993) quoted an incidence rate of 1.8 per 10,000 for children with Duchenne muscular dystrophy. While the Muscular Dystrophy Group does not maintain a full register (While et al, 1996a), they make reference to a similar rate in the male population under 18 years of age. The database maintained by the Society for Mucopolysaccharide Diseases (MPS Society) depends heavily upon the diagnosis of disorders by clinicians. Their data showed there were 299 children living with mucopolysaccharide disease in October 1994, a prevalence of 0.2 per 10,000.

Unfortunately, there are no figures for children living with other life-limiting disorders. Maynard et al (1996) found that the 'special needs' register maintained by the Community Child Health Department was of limited use in estimating the number of children with LTIs living in their area, as a number of important diagnoses were missing (cancer and heart disease). Indeed, ACT & RCPCH (1997) revealed that such local registers were not always based on the same criteria. However, the presence of a comprehensive child health recording system has proven to be successful not only in identifying affected children (NHS Executive, 1998) but also in enabling the team of professionals maintaining the database to have good knowledge of each

child's situation and health status (Wallace & Jackson, 1995). The requirement for robust databases is urgent (While et al, 1996a; Maynard et al, 1996; ACT & RCPCH, 1997). This lack of morbidity data indicates that the need for services for families caring for children over long periods prior to their death is unknown. It is generally accepted that locally-based registers are the best way in which to collect robust morbidity data (ACT & RCPCH, 1997) although it should be essential for each local register to meet recognised national criteria and standards.

2.8 The continuing care needs of children and their families

Families provide for the growth and well being as well as the physical and emotional support of their members. Those families who care for a child with a LTI carry out these responsibilities in the face of additional stresses and needs brought about by that illness (Burr, 1985).

Children have needs which are special to them because they are in a continual state of physical and psychosocial development (Price, 1994). These particular needs of children have been recognised by many government reports (Ministry of Health, 1959; Department of Health & Social Security, 1976; Department of Health, 1991; NAHA, 1988, NHS Executive, 1996). Further acknowledgement occurred with the Department of Health's (1992) initiative to define the needs of children with LTIs and to disseminate information on good practice in the provision and management of services. This initiative provided opportunities for empirical research to evaluate the range of services already provided, and to assess their appropriateness in meeting the needs of families. In addition, it allowed for the identification of gaps in care provision, with a view to developing quality services for families (Soutter et al, 1994; Duncan & O'Flynn, 1995; While et al, 1996a and 1996b). The evaluation of this pilot project programme (NHS Executive, 1998) collated evidence from the 52 projects carried out around the UK. It recognised, among other issues, that every health district needed a senior health service member to: act as a co-ordinator for such children with responsibilities for establishing a source of expertise; set up a mechanism to

oversee comprehensiveness and co-ordination across the district; monitor the caseload and support key workers.

The Children Act (1989) has consolidated much of the previous child care legislation by imposing a general duty upon Local Authorities to safeguard and promote the welfare of children in need. The Act defined a child to be in need if:

- "he / she is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining a reasonable standard of health or development without provision of services by a local authority;
- his / her health or development is likely to be significantly impaired, or further impaired, without the provision of such services;
- he / she is disabled. (section 17(10))".

Further, The Act empowered social services departments (SSDs) to ask other relevant agencies such as health and the voluntary sector to assist with the provision of services as well as to work in partnership with the child and his family.

The UN Convention on the Rights of the Child (1991) established that children have the right to: be protected from harm; take an active part in society; express their views and have them taken into consideration; and to services which meet their needs. All services whether they are responsible for commissioning or providing for children and their families should respect these rights.

Early research regarding the experiences of families showed that they were often under great strain as they lived with the constant 24 hour responsibility of caring for their child, a struggle compounded by the constant threat of the death of the child (Burton, 1975; Voysey, 1975). Nevertheless, Burton (1975) identified that home care and management was preferred by parents who were then better able to shoulder the burden of the child's care themselves. Further, she found that most parents accepted this caring role willingly, viewing it as a challenge and a way of restoring their self-confidence. However, a detrimental effect with accepting full responsibility for their child's

daily care and treatments was that parents felt implicated in the illness outcome and some felt doubly guilty when the child failed to thrive despite their best endeavours.

Childhood LTIs may progress slowly or rapidly. Periods of wellness may be punctuated by acute crises such as treatment interventions. Clinical management and underlying pathological problems for such children are hugely diverse. Baum's (1994) model describing the progression of family burden associated with a LTI highlighted that the particular manifestations of the illness and the speed with which change occurs are factors which significantly affect the needs of the child and family. Throughout the illness trajectory, from diagnosis to bereavement and beyond, families are likely to experience physical, emotional, spiritual and financial distress and potential exhaustion.

So "What do families need?" In answering this rhetorical question Sister Dominica (1990b) proposed that families have a need for: "One person who listens and hears, who recognises *their expertise* with their own child and stays alongside and supports them in their role" (p. 170). While this statement may be true, in reality families, in their daily lives, face a range of continuing care needs which are different for each family every day, and which are unlikely to be adequately met by one professional group or institution (Hinds, 1985; Baum, 1994). These families have a need for a comprehensive and co-ordinated service (Hinds, 1985; While et al, 1996a), involving both statutory and voluntary agencies (Thornes, 1990; While et al, 1996a), which can support them in making informed choices about their needs. Moreover, families need to feel in control of their lives (Stein & Woolley, 1990) and be able to look back on their decisions comfortably (Trapp, 1994).

A number of themes regarding met and unmet family need are recurrent in the literature. Most are specific to distinct disease groups. For example, parents of children with CF have particular needs which are not normally reported alongside research into the needs and provisions for children with

cancer or profound disability. The focus of this study is an exploration of the continuing care needs of families who are neither at the beginning nor the end of their experience with childhood LTI. Gravelle (1997) has defined this part of the illness trajectory as the complex chronic phase where parents have to continuously redefine and then manage the changes resulting from the progressive nature of their child's condition.

The following review on the needs of families draws predominately on the UK literature concerning the needs of families in the following areas: childhood life-threatening illness; chronic illness in childhood; the disabled child; the dying child; the child with special needs; hospice and palliative care for children. There is a paucity of literature pertaining to some LTIs (e.g. congenital heart disease (CHD)), despite the fact that CHD affects 8:1000 live births (Jordan & Scott, 1989). It would be inappropriate to utilise North American literature as health and social care systems are not compatible when comparison is made with those in the UK. It is, however, pertinent to recognise the importance of some seminal works which have extended our knowledge and understanding of childhood LTI and do not have their origins in the UK: (Martinson et al, 1978; Stein & Jessop, 1982; Hobbs & Perrin, 1985; Wallander et al 1989a).

2.9 Information

2.9.1 About the illness

The need for information about their child's illness (While et al, 1996a), how they can support their child's progress and development (Gravelle, 1997), and services available to help them is common to all families caring for a child with a LTI. In the survey of families (n=100) of children with CF (Neale, 1990), five areas of need were identified: three of which related to information, advice and counselling. Information is one of the aspects of care giving most valued by families (Baine et al, 1995, Clare & Pistrang, 1995), yet studies have frequently shown this to be an area where families have expressed a need for additional assistance (Quine & Pahl, 1989; Sloper &

Turner, 1992, Beresford, 1995; While et al, 1996a; Sloper, 1996).

Knowledge and information are pivotal to a family's ability to manage the situation of caring for their child and are only able to exert control over their situation if they receive appropriate and timely information concerning the illness, treatments and prognosis. Beresford (1994) delineated parents into two distinct groups with respect to their need for information. While one group was satisfied with the information with which they had been provided other families actively sought information about their child's condition from other sources. This demonstrated the way in which parents handled stressful or unusual situations and for some, seeking and collecting information was an important part of the coping process. Therefore, information enabled them to develop an understanding of their situation and construct a method of coping with the situation which suited them (Beresford et al, 1996).

The need for information is an ongoing process and does not stop after the diagnosis. Family needs change as the child develops and the illness progresses. Requirement for information becomes more crucial at particular times during the illness trajectory (Beresford et al, 1996) and at times when the child reaches a recognised developmental milestone. These may be times when treatment interventions become intensive or potentially curative as with corrective heart surgery (Wray, 1996), or when the condition deteriorates to such an extent that life for all involved in the caring role changes (Baum, 1994). For example, when a child with muscular dystrophy becomes wheelchair dependent. Developmental milestones include when assessments are made for educational provision (Lavelle, 1994) and in the transition from childhood to adolescence or young adulthood (Eiser, 1993). Families also need to be kept up to date with new treatments (Beresford et al, 1996) and service developments as these too are not static. Over a third (n=36) of the parents (n=99) in While et al's (1996a) study reported that even after their child's disorder had been recognised they still found it difficult to obtain help, information and advice.

2.9.2 At disclosure of diagnosis

While the focus of this study concerns the continuing care needs of families it would be inappropriate to exclude some discussion of their information needs at the time of diagnosis. Although experiences throughout the course of the illness affect the way in which families accept, adjust and cope with their child's death (While, 1989), families have described the imparting of the diagnosis as a key event in their subsequent acceptance and coping with their child's illness (Stein & Woolley, 1990). Beresford (1994) cited two parents who clearly recalled what had been said to them at diagnosis and in both cases it had become central to their attitudes and approach to the care of their child. The disclosure of any abnormality is a severe shock to parents, and the manner in which it is carried out is likely to be vividly etched in their memories (Halliday, 1990). Stein et al (1989), in their evaluative study of the first children's hospice (Helen House), found that parents (n=45) caring for children with chronic LTIs were preoccupied with memories of the initial diagnosis interview and the way it had been conveyed despite this having occurred many years previously. Green and Murton (1996) also reported families to have a vivid recollection of the disclosure interview, although, their quantitative data analysis appeared to contradict this in that they reported 70% of parents as not understanding or remembering everything said at this interview.

Conveying a diagnosis of LTI has been the focus of a number of studies which have found dissatisfaction with both the disclosure process and the content of the information given (Greenberg, 1984, Cottrell & Summers, 1990; Sloper & Turner, 1993; Green & Murton, 1996; Sloper, 1996). The way in which parents are informed of the diagnosis undoubtedly affects their relationship with professionals involved in the process (Beresford et al, 1996). Indeed relationships may be impaired if information is imparted unsympathetically (While et al, 1996b), without attention to privacy and timing (Neale, 1990), with little opportunity for information to be repeated and clarified or for questions to be asked and discussed (Woolley et al, 1989a). While presenting a "rosy" picture or raising false hopes of the prognosis is

undermining rather than being supportive (Heggarty, 1994), the issue of knowing the truth, however, negative, was important to parents of children with cancer interviewed by Sloper (1996) as all but three (n=98) wanted to know everything.

More recent studies which have investigated the most important factors predicting parental satisfaction (Sloper & Turner, 1993; Green & Murton, 1996) can be used to inform practice. Beresford et al (1996) succinctly outlined the evidence concerned with structural procedures, factors associated with the manner of telling and information imparted as well as organisational aspects required of professionals when disclosing a diagnosis to children and their families. Families in Green and Murton's (1996) study placed greater importance upon the manner of professionals and the content of the information than on structural procedures. A finding supported by Cottrell and Summers (1990) in their longitudinal study of five families caring for children with severe disabilities where parents were not, for example, dissatisfied if reasons for a delay in disclosure of the diagnosis were justified and every effort made by professionals to explain them. This is contrary to the early work of Burton (1975) who discovered that a delay in diagnosis generated feelings of hostility and mistrust towards the medical profession. The main reason reported by While et al (1996a) for parental dissatisfaction during the diagnosis period related to the length of time waited to obtain a diagnosis, with over a third of families waiting longer than six months. Nevertheless, 23 of the 58 respondents reporting dissatisfaction during the diagnosis period gave reasons which related to advice or information.

Clearly there are difficulties in communicating diagnoses for LTIs whose aetiologies and prognoses are not clear (Green & Murton, 1996) or with an evolutionary diagnosis (Cottrell & Summers, 1990). Indeed, with the improved prognosis of childhood cancer (Stiller, 1994) health professionals have to balance an awareness of the possibility of death with the realistic hope of a child's survival, when conveying information to parents (Koocher & O'Malley, 1981). Green and Murton (1996) proposed that the success of parents with higher education in obtaining adequate information may reflect a

greater likelihood of being able to ask the right questions or may be related to the doctors' perception of the parents' informational needs. In addition, they postulated that this may also be due to the fact that doctors find it easier to talk to people who are more like themselves. A fact which may be disputed by health professionals but one which should be borne in mind when communicating with families. This supports the premise that another professional should be present at the disclosure interview, someone who can support the family immediately afterwards to check their level of understanding and develop a preliminary plan of care. The early recall interview with the consultant or GP suggested by Green and Murton (1996) can assist in this process. However, this should not take the place of a keyworker able to visit the family home and develop a greater understanding of family need which can then be utilised within the multidisciplinary framework (NAHA, 1988) to mobilise appropriate services.

2.9.3 Service provision

Difficulties in obtaining information about appropriate services may exacerbate stress, while appropriate responses from services can be an important resource for families (Sloper & Turner, 1992). However, in reality information concerning services and the types of benefits available can often be inaccessible. This is perpetuated because of the variety of services offered by the different provider agencies; health, education, social services and voluntary organisations. For example, Sloper and Turner's (1992) study showed families (n=107) to have been in contact with an average of 10 different professionals during the previous year, with most frequent contact being with physiotherapists, teachers and hospital doctors. While findings from Beresford's (1995) national survey revealed 60% of families had seen between five and nine different professionals about their child in the previous year. Most frequent contact was with the child's GP, teacher, hospital consultant and HV. Interestingly, 54% of families had not seen a social worker, while 9% of families had not visited their GP and 14% of pre-school children had not seen their HV.

Parents do not always know where to obtain the information which would help them locate appropriate services (Sloper & Turner, 1992). Families who take a passive approach to dealing with their child's problems may be less likely to find an appropriate service. The provision of information about services may help parents take an active role to obtaining appropriate help, a view confirmed in Beresford's study (1994), where parents who actively sought information were better able to demand the level of services their child was entitled to. The use of information seeking strategies places parents in a position of power.

The information needs of those with literacy problems and from ethnic minority groups need particular attention (Shah, 1992). Information is always required in minority languages (Neale, 1990) and in a form accessible to all parents. Quine and Pahl (1992) found that where information booklets were available families were less likely to express the need for information about services. Voluntary organisations produce a range of good literature which can be passed to children, families and professionals (Rees et al, 1989; Lavery, 1990; Contact-a-Family, 1991; CF Trust, 1993; ACT & RCPCH, 1997). This material can be given to family members and friends as a means of accessing more support from the extended family and social network to encourage a greater understanding of their situation (Palmer, 1994), although, attention needs to be given to their readability and presentation (Beresford et al, 1996).

A number of ways of improving information sharing and communication processes have been discussed in the literature. For example, the use of the Parent Held Record with appropriate additional pages to the National Parent-Held Child Health Record for sick and disabled children provided parents with a written summary of their child's progress (Macfarlane, 1992; Vaz, 1995). Families also used them in their consultations with other professionals (Beresford et al, 1996), and, if other liaison methods fall short, this may be the only communication route (RCN, 1994). One benefit of encouraging parents to comment on services in such records means that they may also be a useful method of auditing services. Cowper and Lenton (1996)

evaluated the practice of sending individualised letters to parents after paediatric consultations, with copies sent to GPs rather than the previous practice of sending a letter to the GP only. They reported very favourable responses from parents who felt valued by the professional from whom they received the letter. In addition, this practice aided understanding and provided an opportunity to recap on information which families were unable to take in fully during the consultation. It also enabled them to share information more easily with family members, friends and other professionals.

Support offered by professionals in Beresford's study (1994) was often in the form of information about local services, benefits or accessing other services. Families (n=45) interviewed by Woolley et al (1991) felt greatly helped by professionals who had knowledge of available services and material benefits. Although, Beresford's (1994) study showed that parents who met either informally or formally through a support group were a crucial source of information to each other particularly about practical issues such as benefits, respite care facilities and schooling. Families with older children used the support group as an important source of information about how they had overcome difficulties and how they could share their experiences and give advice to other parents.

Further research is needed to explore differing methods of information giving by professionals as the type and detail of information preferred differs between families and by families at different times during the illness trajectory. To ensure families receive all the information appropriate to their requirements an individualised approach is necessary with families being able to choose from a variety of options (Beresford et al, 1996). The involvement of families in the development of information resources can help to ensure that information is accessible to all groups and communities and that information services are appropriate and meet family needs. A collaborative approach adopted by professionals and parents in one health authority resulted in the development of a written guide for parents. This demonstrates the usefulness of initiatives at local level which can be

successful in responding to the needs and views of families and improving parents' access to information (Maynard et al, 1996).

2.10 Equipment and resources

2.10.1 Medical equipment

Families have a need for help with medical equipment and aids to daily living (Meltzer et al, 1989; Curnick, 1990; While et al, 1996b) to facilitate provision of care. Indeed, care for children at home cannot be successful unless appropriate equipment and aids are available to be loaned out as and when they are required (Kohler & Radford, 1985; Goldman, 1990). However, there is often friction between agencies over the provision of medical equipment (Audit Commission, 1994).

Studies have demonstrated deficits experienced by families concerning medical equipment. Indeed, a third of the families interviewed in Soutter et al's (1994) study expressed a need for equipment to be readily available. A similar number (38%) of families (n=45) reported major expenditure with equipment and household issues (Woolley et al, 1991). Working party evidence has recommended that a clear mechanism for the accessibility and funding of medications, disposable medical and nursing supplies and medical equipment should be developed by health authorities. In addition, the provision of medical equipment and disposables may be more efficiently achieved through one source rather than attempting to coordinate their provision via an array of different statutory and voluntary sources (ACT & RCPCH, 1997).

2.10.2 Aids to daily living

Creating a good environment for managing a disabled child's care can require both special medical equipment and furniture as well as ordinary consumer items such as a freezer, microwave, video, CD player and computer. All such items help hard pressed parents cope with and improve

their child's quality of life (Beresford et al, 1996). The need for such items and for their more frequent replacement is a common theme in research which has been carried out (Smyth & Robus, 1989; While et al, 1996a). Indeed, Baldwin and Carlisle (1994) found this theme running through the studies which they reviewed, and concluded that ownership of consumer durables, which facilitated the absorption of the demands of caring for a disabled child, was actually lower among families of children with disabilities than in the general population.

While et al (1996a) distinguished between disability equipment, special equipment and special furniture in their study. They found the most commonly used types of special equipment were nebulisers and physiotherapy wedges. This reflected the needs of children with CF which represented one of the main disorder groups (13%) of their sample (n=99). In addition, 68 of their respondents reported using some form of special furniture to assist their child's personal care and comfort, while a quarter (n=26) reported the use of a special bed and a third (n=35) a special chair. An alternative to focusing on deficits and negative aspects of disability is to study how and why some families cope better than others when faced with childhood disability and LTI. Concerning equipment, Beresford's (1994) study showed how parents were able to use disability benefits and material resources to enable them to care for their child by purchasing aids to daily living although they felt that these should have been provided by statutory services. Other purchases, although less essential, aided comfort, safety or happiness, for example, clothing, a car seat and satellite television for an immobile child.

Working party evidence (ACT & RCPCH, 1997) concluded that along with medical equipment, all aids should be available centrally in every district with access for all those providing care (health, social services and education). A mechanism is needed, however, to avoid the frequently reported wrangles and confusion between SSDs and health over funding for items such as special chairs and beds (Audit Commission, 1994).

2.10.3 Transportation

The difficulties and costs of getting out and about are a major preoccupation for the great majority of families caring for a disabled child (Smyth & Robus, 1989; Beresford et al, 1996). Sloper and Turner (1992) reported that 38% of their sample (n=107) had unmet needs regarding transport. Difficulties in using public transport make it important to have access to a suitable car. The costs of having an appropriate vehicle can often be considerable as they need to be large enough to accommodate wheelchairs, other equipment and family members. In addition, because of their frequent use they may have to be replaced more often (Beresford et al, 1996). Further, Beresford found in her (1995) study that only 50% of parents (n=1227) interviewed had access to a car, a figure lower than the general population, two thirds of whom are car owners.

Regardless of the nature of the LTI, transport costs for families are likely to be increased for hospital appointments and therapy sessions (Hill, 1994). Woolley et al's (1991) study (n=45) found 67% of families reported major expenditure with transport for hospital visits, inevitable for families living in rural and isolated areas. Travelling by taxi, although expensive, was preferable to public transport for some families in Beresford's (1994) study because of the child's social and communication impairments. Other families felt that public transport was unsafe and when used for school journeys meant that their child was away from home for a very long time. Meeting extra transport costs was the most common use of the mobility component of DLA benefits, although, interestingly, parents who did not receive the mobility component also most frequently used their benefits to pay for the additional costs of transport (Beresford, 1994). The mobility component of DLA is not available for families of children aged under five years (Howard, 1995) although children with progressive degenerative disorders and profound disability less than five years of age often require special forms of transport. Indeed, Beresford (1995) reported a greater proportion of families with younger children describing extra transport costs than families with children over five years of age.

2.11 Coping strategies and resources

The provision of services for childhood cancer has frequently been a model for conducting psychological research in other LTIs (Eiser, 1994). In 'making sense' of chronic illness, Eiser identified three distinct phases in the history of cancer treatment and research in children. During the 1950's, the focus lay with caring for the child and in preparing the family for the inevitability of the child's death. Advances in cancer treatments, during the 1960's and 1970's, led to considerable improvements in survival rates which, not only caused a significant increase in interest in childhood cancer but also saw a shift in the emphasis of research, with studies focusing on living with a LTI. Researchers focused primarily on the functioning and experiences of mothers despite acknowledging the pivotal role of 'the family'. Children receiving treatment in the 70's and 80's lived longer and as a consequence of the disease or treatments it became apparent that they experienced considerable physical and psychological side effects. Research which measured the extent of the adverse effects on children and families began to dominate the psychological literature (Koocher & O'Malley, 1981; Spinetta & Deasy-Spinetta, 1981).

The practice and wisdom of measuring psychiatric disturbance in children with cancer is currently being challenged, as children with LTIs are not psychiatrically disturbed (Eiser, 1994). Rather, they are ordinary children who are obliged to cope with extraordinary circumstances (Bradford, 1997). Thus, it may be more helpful to the child if the focus of research and interventions lay with investigating how children and their families cope with their situation (Beresford et al, 1996). Presently, the focus for research has shifted even further towards living with a chronic illness with the emphasis firmly on the child as a member of a dynamic family system. Now research which informs interventions and practice, centres on assisting the child and family to manage their experiences and to minimise the effects on their daily lives. In addition, extending knowledge and understanding of why some families fare better than others when faced with a similar set of circumstances is perceived as being of paramount importance (Davis, 1993; Eiser, 1994).

Adopting a perspective which looks at how children and their families cope with stress has meant that research has focused on factors such as resilience and coping processes. Wallander et al (1989a; 1989b) proposed a model which took into account several variables such as the disorder, as well as social, family and other cultural factors which may influence resilience and adjustment. Both Eiser (1990) and Bradford (1997) have argued the case for such models which identify coping resources available to families. Many researchers have favoured the process model of stress and coping (Lazarus & Folkman, 1984). This model asserted that the extent of the negative consequences of stress which affect a person are more to do with the process with which a person copes with the stressor than with the severity of the stressor itself. Further, they proposed that the principal components of the coping process were two factors: coping resources and coping strategies.

Families use both socio-environmental and personal resources to manage stressful situations or events and a multitude of factors influence the coping process (Baldwin & Carlisle, 1994). These not only determine how a family assesses their situation and circumstances and how stressful they perceive their situation to be, but also determine the coping strategies which can be developed and used to manage stressors. Resources such as information, money, practical resources, respite care, emotional and other types of social support are used by families on a daily basis in order to cope with their situation. On a personal level, factors which influence the way in which parents manage a problem or situation are defined as their beliefs and approach to life, their physical and mental health, aspects of their personality and the skills they possess (Beresford et al, 1996). Several socio-environmental coping resources (money, information, practical resources, respite care and social support) are discussed elsewhere in this review. The coping resources families have available to meet their emotional needs are of primary importance. Although routine specialist support from psychologists may not be required as long as other support mechanisms are in place (NHS Exec, 1998), the main burden of caring for a child with a LTI is invariably emotional (Burne et al, 1984; While et al, 1996a). Some difficulties cannot be completely alleviated and therefore have to be endured. Thus, the purpose of

the development of coping strategies can either be to master the source of the stress or manage the distressing emotions caused by the stressor. Baldwin & Carlisle (1994) concluded that greater levels of family well being are associated with the use of active coping strategies such as planning, information seeking and problem solving. Coupled with the coping resources available to them these influence their well being to a greater extent than those factors which have previously been the subject of research, such as, the severity of the illness or disability and the degree of care needs (Beresford et al, 1996).

Thus, families have a need for coping resources and a need to develop coping strategies to assist them in their caring role. This review focuses on four areas of concern: caring for the child; managing the situation; caring for the immediate and extended family; and planning for and coping with the future.

2.11.1 Caring for the child

Several studies have found that families desire information about the nature of their child's illness and its likely progression. This enables them to understand and make sense of what is happening and assist them in planning for the future (Burton, 1975; Quine & Pahl, 1989; Sloper & Turner, 1992; Stein & Woolley, 1990; Canam, 1993; Jerret, 1994; Beresford, 1995; While et al, 1996a). Coyne (1997), in her review of the literature pertaining to the importance of support for caring for a child with CF, identified the principal effective coping strategy as ability of families to assign meaning to their child's illness.

The alleviation of their child's physical and emotional symptoms is of major importance to families. Many physical symptoms are distressing causing the child to require psychological and spiritual support (ACT & RCPCH, 1997). Families willingly undertake day to day symptom management often involving complex nursing care (Kirk, 1998), although, they should have 24 hour access to knowledgeable support in times of crisis. Families in Stein &

Woolley's (1990) prospective controlled study (n=42) most frequently expressed worries about their ability to continue caring for their child and their capacity for coping on a daily basis particularly if their own health should become fragile. Furthermore, they expressed concerns about the child's symptoms, course of the illness and about the child's ultimate death, in particular, how death would occur and how they would manage the situation.

Respite care provision will be discussed at length. In addition, however, it is important to recognise that obtaining a break from the burden of caring is an essential coping resource. More than half the mothers (n=21) of children receiving hospice support interviewed by Stein & Woolley (1990) particularly valued the fact that regular respite breaks were planned in advance regardless of their child's health status (i.e. relatively well or acutely sick). Access to an emergency bed during a family crisis period was also revealed, highlighting the need for contingency respite care plans to be in place to reduce parental worry and sense of isolation. This enabled them to recharge their batteries and keep up with the caring demands at times in between. Favourable qualities of hospices such as: homely environment; care for the whole family; high nursing staff: patient ratio; nurses familiar with problems associated with rare conditions are sought by families. They need to be certain that the care provided meets their own standards and that their child's familiar routine is continued, in order to be confident to delegate the caring responsibility (Whyte, 1992; ACT & RCPCH, 1997). Children's hospices actually provide the opportunity for holidaying altogether for those families who are unable to leave their child (Hill, 1994). Finding trustworthy child care is another important resource needed by families. Some children's care is very complex and child-minders or baby-sitters entrusted with care need good training and support and to know the child well. Furthermore, mothers (n=42) in Stein & Woolley's (1990) study felt very housebound as they described difficulties in finding a suitable minder.

2.11.2 Managing the situation

For the majority of children the responsibility of daily care at home rests with

their parents. Jerrett's (1994) phenomenological study of families (n=10) caring for children with juvenile arthritis found that parents' interpretation of their situation was based firmly upon the belief that the responsibility for their child's care lay with them. Further, the successful management of their child's illness revolved around the family being able to continue with the prescribed care following discharge from hospital. As with information the development of expertise with caring practices also empowers families and enhances a family's personal coping strategies. One of the main tasks common to families caring for children with LTIs which positively influences adaptation is managing their child's care on a day-to-day basis (Canam, 1993). The formation of positive relationships with health professionals enhances parents' ability to utilise them as a coping resource to obtain information and develop a body of practical knowledge and expertise (Beresford, 1994). In addition, in Gravelle's (1997) phenomenological study, families (n=11) managed change related to their child's condition and care requirements by: actively seeking information, making preparations and plans for the future, rearranging their daily lives to accommodate their child's additional requirements, negotiating with service providers and using existing resources such as respite care. While experiences of being let down by services and conflicts with professionals were reported by parents (n=20) in Beresford's (1994) study who felt unsupported in their situation.

Personal well being is enhanced by effective social support (Dunst et al, 1994). Establishing a system or social network of support therefore facilitates a family's coping processes and enables them to maintain meaningful relationships with others and manage the situation effectively (Canam, 1993; Gibson, 1995). Nevertheless, the challenges of care-giving which impinge on a family's time, energy and personal resources often inhibit the development of a supportive network, thus increasing the chance of a family becoming social isolated (ACT & RCPCH, 1997). This premise is supported by the work of Florian and Krulik (1991) who revealed that Israeli mothers (n=90) caring for children with either LTI or chronic illnesses reported higher feelings of loneliness in comparison to mothers in their control group. Further, they demonstrated that for the group of mothers (n=33) of children with LTI,

severity of illness was associated with significantly higher loneliness scores with mothers reporting significantly smaller amounts of social support. The most significant sources of informal support are to be found in relationships with the immediate and extended family (Peace et al, 1992). Additionally, other informal sources are friends, neighbours, work colleagues, religious or spiritual friends and those met via the child's school network (Brown & Hepple, 1989). Formal sources of support come from the array of different statutory and voluntary services (Beresford et al, 1996).

Social support is an influential interpersonal factor in the process of empowerment of families (Gibson, 1995). Gibson's (1995) study exploring the process of empowerment in mothers (n=12) of chronically ill children found that the majority drew support from someone in a similar situation. More than two thirds (69.7%) of families (n=99) in While et al's (1996a) study reported that they maintained contact with others in similar situations. Gibson (1995) further noted that sharing experiences meant that families gave as well as received support, and were able to encourage and learn from each other. Clearly, association with other mothers in this study was a beneficial source of support and thus an important coping resource. Such support is facilitated in specialist / tertiary centres (Duncan & O'Flynn, 1995) where families have contact with others. It may be more problematic when the child's condition is very rare or the diagnosis delayed, or when care is shared with primary or secondary health services where there is likely to be limited contact with other affected families.

Providing families with the opportunity to join or belong to a support group is a helpful strategy to assist parents in coping with their child's LTI (Stein & Woolley, 1990). Indeed, Lavery (1990), from personal experience, commented that professionals are at last recognising the value of "parent-orientated self-help groups" (p. 129), although, Eiser and Havermans' (1992) study, which identified coping patterns in parents of chronically sick children, found that some parents perceived self-help organisations as unhelpful in meeting their needs. Others however, reported involvement ranging from minimal contact (i.e. reading the newsletter) to those who expressed a

greater commitment, for example, by attending meetings and actively fundraising. Nevertheless, parents (n=1227) in Beresford's (1995) national study, a third of whom belonged to a support group, reported a number of benefits. These included an opportunity to talk with other parents, and to exchange all kinds of information, for example, concerning their child's condition, local services and making plans for the future. Having cared for her son with MPS, Lavery (1990) spoke with experience regarding her feelings of "isolation and ignorance" (p.125) in 1976. Yet, 15 years on, in her role as National Development Officer with the organisation Contact-a-Family, she reported receiving over 1000 enquiries a year from families trying to get in touch with those in a similar situation. Astonishingly, a self-help group exists for most families who seek information. In addition, some groups offer the chance for children with similar conditions to meet each other (Beresford et al, 1996). Disease specific genetic counselling and family support groups are the most common forms of coping resources available to families in the UK (Midence et al, 1993).

Mothers with low socio-economic backgrounds and low levels of social support are more likely to take advantage of group support when such services are offered to them (Dale, 1996). However, Beresford et al (1996) concluded that families on low incomes and those from ethnic minorities were less likely to be aware of support groups. The evidence suggests that these families have most to gain from belonging to such groups thus it is important for service providers to improve both their methods of informing about groups and about reaching those most in need.

Despite the difficulties experienced by parents, most appreciate the need to minimise the impact of the illness on their family (Eiser, 1990). A family's ability to adjust to the illness and enable life to carry on as near normally as possible has not been the focus of past research. However, most families appear able to mobilise a variety of coping resources and strategies in order to reduce the effect of their situation (Lazarus & Folkman, 1984, Wallender et al, 1989a; Eiser, 1990; Davis, 1993; Bradford, 1997). Normalisation is a key coping strategy enabling families to minimise the impact of their child's illness

enabled them to meet their child's normal developmental needs (Canam, 1993). However, it is often very difficult for the family to behave as if life is normal (Thomas, 1994), a view supported by Duncan & O'Flynn's (1995) exploratory study which reported families (n=18) to have difficulty in their efforts to maintain normal family life. Undertaking social activities causes particular problems, for example, a third of families (n=99) in While et al's (1996a) study were unable to visit the cinema with their child.

The practical demands on parents caring for children with LTI coupled with emotional consequences means that parents often have less time to spend together. Having the opportunity to relax together away from the home environment is further complicated by difficulties in finding a trustworthy baby-sitter able to deal with the child's extraordinary needs (Eiser, 1990). Sabbeth and Leventhal (1984) critiqued the literature concerning marital adjustment in families of children with chronic illnesses and concluded that despite their difficulties the average divorce rate was no higher in such families. Nevertheless, the strain on the marital relationship is considerable (Stein et al, 1989; Baldwin & Carlisle, 1994). More than half of the parents in While et al's (1996a) study who were separated (n=12) felt that their child's illness had contributed to the breakdown of their relationship, while only a minority (20.5% n=99) felt that their marriage was not affected by their child's illness. Thirty percent of two parent families (n=25) in Stein et al's (1989) retrospective study revealed that they experienced substantial problems in their marriage. This finding was confirmed by While et al (1996a) who reported a similar number (33.3%) of couples to be experiencing negative effects such as stress and strain. Nevertheless, factors which determine whether such stresses influence dysfunction or enhance partner relationships need clarification (Eiser, 1990). Indeed, While et al (1996a) revealed 30% of families reporting positive effects on their relationship, although they were unable to conclude which factors facilitated the beneficial effect.

Parents have a need to balance the time and energy they spend in caring for their child with the time they have for other immediate family members or personal time for themselves. Many parents describe a rushed family life

(Duncan & O'Flynn, 1995) and not having enough time during the day for normal daily activities. Mothers in Gravelle's (1997) study reported that feelings of constant tiredness dominated their lives as their child's needs often precluded them from undertaking other essential activities. Time is a precious commodity for families and their child's quality of life often takes precedence (Goldman & Baum, 1994). Gravelle (1997) also revealed that families (n=8) used several strategies to manage the large amount of time spent in the care-giving role. In particular, mothers needed to re-negotiate their daily activities as their child's needs increased, a view supported by parents (n=10) in Jerrett's phenomenological (1994) study which revealed the value of creating a well organised routine which enabled families to cope with their caring activities.

2.11.3 The immediate and extended family

The needs of brothers and sisters to a certain extent mirror the needs of the sick child in that they need to know what is happening and why, and what is likely to happen in the future (Trapp, 1994). However, healthy siblings also have distinct needs which require investigation. The well sibling may feel responsible for causing the illness in some way or anxious that they may also become ill (Eiser, 1990). Research studies have revealed that healthy siblings do have an increased risk of experiencing emotional and behavioural problems (Burton, 1975; Cairns et al, 1979; Lavigne & Ryan, 1979; Drotar & Crawford, 1985; Lobato et al, 1988; Martinson et al, 1990; Breyer et al, 1993), particularly during the early stages of the illness when parents may focus their attention and energies on the sick child (Eiser, 1990). Nonetheless, further research has shown that there is substantial variability in healthy siblings' responses to LTI, with both negative and positive reactions being reported (Stewart et al, 1992; Havermans & Eiser, 1994; Stallard et al, 1997). A useful review of the literature, which outlines studies' foci, their location, methods and findings, has been performed by Williams (1997) who identified over 40 studies investigating the extent and characteristics of risk factors affecting siblings of chronically ill children. Indeed, nearly 60% of the studies she reviewed reported an increase in risk

to well siblings, while 30% reported no risks, with the remaining 5 studies reporting positive effects attributable to experiences with the sick child.

Anderson and Crawford (1995) revealed that siblings (n=29) aged between eight and 16 years expressed feelings of jealousy regarding the amount of time parents spent with their disabled child. Anger at the extent of restrictions placed on family activities, social isolation, being different from their peers, and experience of teasing and bullying at school were also reported. Some children may be unwilling to express such difficulties at home for fear of burdening their parents further (Havermans & Eiser, 1994). However, sibling groups have been useful in meeting the needs and providing support to siblings (Mikkelsen, 1993a; 1993b). Stallard et al, (1997) confirmed that healthy siblings (n=52) of children with LTI had significant communication and information needs yet felt unable to approach their parents or anyone else about their problems. This was particularly significant for siblings aged less than 12 years who also expressed more positive feelings about the prognosis of the ill child. A lack of provision of information to younger children may reflect the uncertainty felt by parents regarding what aspects of the illness they should share with their children or it may be a general response to talking about painful and distressing events. Clearly, services have a role in empowering and facilitating parents' ability to recognise the importance of communicating openly and sharing age appropriate information with their children. Havermans and Eiser (1994) concluded this to be a critical aspect of practical concern. Further, parents need to be aware that if well children do not raise issues, then this does not signify that concerns about the sick child do not worry them.

Family characteristics and coping resources may modify the emotional responses of well siblings (Eiser, 1990), therefore, interventions which are successful in supporting parents are also likely to have a positive effect for well siblings (Beresford et al, 1996). Life-threatening illness affects all family members and their emotional responses are entwined and interdependent, therefore interventions which focus on one part of the family alone is unlikely to be completely effective (Eiser, 1990) as they do not consider the personal

coping strategies used by other members (Beresford et al, 1996). However, it is important for researchers to investigate the factors which differentiate those children who experience problems from those who do not (Beresford et al, 1996). Somewhat controversially, Stallard et al (1997) recommended that parents should be encouraged to 'make' time to enjoy "the normal aspects of non-illness related family life" (p.22) with their healthy children. However, in reality the solution is not that simple as many families do not have the essential socio-economic and emotional coping resources and strategies in place to be able to make time, and may therefore be disadvantaged.

Work concerning family adjustment to LTI has focused principally on the mother and child dyad. Services which focus solely on the child may not be aware of other problems in the family. Moreover, some services may actually increase the care demands on the family by appearing to expect parents to concentrate on the sick or disabled child to the exclusion of other family members or other problems (Sloper & Turner, 1992). However, as with healthy siblings, these other members of the child's immediate family also have considerable and distinct needs which require investigation and support interventions (Beresford et al, 1996). Very little research has been done to enhance our knowledge about the role fathers or grandparents play in families of sick children. Mothers are generally more involved with services as home visits and hospital appointments usually happen when the majority of fathers are at work, thus most fathers are dependent upon mothers for information about their child's progress, treatments and interventions. Such lack of first-hand information may foster feelings of frustration and being side-lined (Beresford et al, 1996). Further, if the information conveyed is considered insufficient by fathers this may cause tension. This may contribute to problems with family unity and thus impinge on the amount of support fathers wish to provide. Indeed, Stewart et al's (1992) controlled study of healthy siblings and their parents (n=10 couples) reported that a response to childhood LTI expressed by some fathers was to withdraw from family life.

Needs expressed by fathers themselves have only received minimal

investigation and the validity of research which relies on mothers' perception of fathers' views has been questioned (Eiser, 1993), although, this view is not supported by Cottrell and Summers' (1990) interview study of families (n=5) who participated in a support group. They revealed that a delicate balance had built up where mothers cared for the child and fathers cared for the mother. Fathers were not allowed to show too much distress as this was perceived as upsetting for, rather than comforting, to mothers. In addition, all mothers thought their partners would benefit from a support group but that they would refuse to participate, and when interviewed separately, fathers were not in favour of attending a group. Those studies which have elicited the views of fathers have shown that they do experience stress with 39% of fathers (n=72) in Sloper and Turner's (1993) study of factors affecting adaptation in families of severely disabled children scoring above the cut off point on the parental distress questionnaire. However, the study did not illuminate the reasons for such high levels of psychological distress, which may be due to the severity of the disability or to the two time periods on which the study focused (diagnosis and starting formal education), or a combination of both.

Those studies which have compared the needs of both parents have found evidence of differences in their worries and methods of dealing with a situation. In particular, McConachie (1991) in her study concerning how parents (n=17 couples) carry out teaching and therapy sessions with preschool disabled children found that fathers were receptive to carrying out therapy tasks as requested by the study particularly during the evenings and at weekends. Thus, when planning intervention strategies, services should not underestimate the willingness and potential skills of fathers. Beresford et al, (1996) recommended a shift in the usual pattern of service provision with flexibility a key aspect in the timing of appointments. Nevertheless, the differing needs of fathers cannot be met until research and interventions are designed specifically to identify and respond to their needs.

The role of grandparents is often seen as one for providing childminding for the well siblings and support for parents, but, no studies have been done to

explore either their responses to LTI or their needs (Black, 1994). Therefore, gaining understanding of the grand-parental role and involvement is important for those planning research and practical interventions (Burns & Madian, 1992). Grand-parents can be either a source of immense support or an additional stressor for parents. Like other members of the family, they have specific needs in that they are in the unenviable position of experiencing double grief and pain, firstly for their child (the parent) and secondly for their grand-child (Trapp, 1994). In addition, they rarely receive information first-hand and thus may have difficulty in understanding the condition and treatments (Black, 1994). Their feelings of dis-empowerment are heightened by a sense of guilt that they may survive their grand-child and that they may not have an opportunity to express their feelings for fear of adding to the parents' burden (Burns & Madian, 1992).

2.11.4 Coping with the future

The nature of many LTIs means that although death is certain the course of the illness is unpredictable, consequently many families live with varying levels of uncertainty. This concept was the subject of Cohen's (1995) qualitative study using the grounded theory method (Glaser & Strauss, 1967) with interviews from a sub-set of families (n=10) who were participating in a five year longitudinal study regarding the impact of childhood cancer on families (n=40). At diagnosis, feelings of uncertainty are pretty intense and constant, however, Cohen (1995) suggested that those families providing continuing care to their children experience a different form of uncertainty. For these families, uncertainty is something which changes over time and intrudes into their lives periodically. Further, she identified the following seven 'triggers' which caused an increase in the level of awareness of uncertainty: routine medical appointments; changes in their child's behaviour or functional status; keywords and provocative questions; changes in drug therapy and management or the advent of a new surgical intervention; evidence of negative outcomes for example, via the media; demands imposed by developmental milestones; and night-time (i.e. absence of distraction at night). In addition, she proposed that parents develop strategies to cope with

their responses to uncertainty, both intentionally and by trial and error. One approach used by parents is to live 'one day at a time' (Lavery, 1990), a strategy also employed by Halliday (1990) who spoke from personal experience when describing his own family's difficulties with being unable to plan ahead for "fear of disappointment" (p.21). Moreover, Cohen (1995) deduced that health professionals may actually increase parental distress by unwittingly 'triggering' an increased sense of uncertainty when they mistakenly assess parents, who are trying to attain or retain family normality, as being in denial. While the assessment process itself does not cause stress, interventions initiated to counter parental denial may increase awareness of the child's future uncertainty.

Research has shown that planning for future needs and events required information and counselling (Neale, 1990) in that information is needed well in advance of any choices and decisions having to be made (Beresford et al, 1996). Gravelle's (1997) phenomenological study of 11 families exploring the day to day experiences of parents caring at home for a child with a progressive LTI, showed that all parents looked ahead to a certain degree in order to prepare themselves for the future. The planning process was very important as families wanted to ensure that their child's continually changing health care needs would be met smoothly. This is contrary to the findings in Burton's (1975) seminal work where parents acknowledged the burden of their caring role but over three quarters preferred not to plan ahead or think of the future.

2.12 The additional costs of caring

Families of children with LTIs are at greater risk of financial disadvantage because of the "extra" costs caused by the disability (Beresford et al, 1996). Smyth and Robus (1989) in the OPCS surveys of disability in the UK reported that the majority of families (n=1144) incurred additional financial costs as a direct result of having a disabled child. Other research has shown that material resources as well as money are important factors in the alleviation or prevention of distress in mothers (Wallander et al, 1989a; Quine

& Pahl, 1991; Sloper & Turner, 1993; Beresford et al, 1996).

Meeting the child's needs for care and support hinders parents' ability to earn (Baldwin, 1985; Smyth & Robus, 1989) and the demands on time create difficulties with careful housekeeping and often means that families have to change their priorities, (for example, taking holidays in the UK rather than abroad), particularly when the child has an acute illness, is hospitalised or more simply needs stimulation or entertainment. The combination of reduced income and extra demand for money may cause the family to experience financial pressures. Research has verified that the nature of financial pressure is pervasive although it is often difficult to recognise that families are under financial pressure because of the ways in which they manage their lives and keep up appearances so well (Beresford et al, 1996).

The material resources needed by the family can be considerable for them to manage effectively their child's condition and to minimise its impact on their quality of life. Needs vary with particular LTIs and often with age, but common themes voiced by parents are for suitable housing, appropriate equipment and convenient transport all of which can involve considerable capital outlay (Beresford et al, 1996). Measuring the extent of extra costs is problematic. Baldwin and Carlisle's review of the literature (1994) revealed a variety of different approaches and differing estimates in the level of spending on individual items and in total. Beresford's study (1994) concluded that parents on very low incomes absorbed some or all disability benefits into the general household purse. This prevented money being used to facilitate caring through the purchase of a car, help with household duties or child minding. Other parents used DLA to cover the extra costs caused by the child's disability, although rarely was any money left over to meet their own needs in caring for their child. Those parents who were able to use disability benefits to relieve the burden of care did so by paying for assistance with household chores and child care (Beresford, 1994).

2.12.1 Aids and equipment

Extra spending may be needed for something specifically related to the LTI, for example, medical supplies for items such as a suction machine or nebuliser. Special equipment is not always readily available through health service sources, while mobility, bath and lifting aids, special beds and chairs are examples of things which families often have to purchase or fundraise for (Hill, 1994). Ordinary household goods and utilities such as electricity or a washing machine also require additional expenditure. In general, the needs of the child frequently mean that the family is faced with larger bills for clothing, bedding, heating and transport costs (Quine & Pahl, 1989; Smyth & Robus, 1989; Beresford, 1995; While et al, 1996a). Further, these studies have reported that families regularly spent extra on disability or illness related items, such as chemist items and food supplements (Stein & Woolley, 1990).

2.12.2 Housing

A principal concern and expense for families is creating a suitable home environment. Families of children with LTIs are more likely than others to be living in accommodation which they consider to be inadequate or unsuited to their child's needs (Beresford et al, 1996; While et al, 1996a). Difficulties reported by parents are features which make caring difficult, for example, stairs, lack of space, privacy and access problems (Baldwin, 1985; Beresford, 1995; While et al, 1996a). When families can afford to they deal with such difficulties by adapting their houses, moving house or both. Almost half the parents (n=1227) in Beresford's (1995) study had moved to a new house because of their child's needs, while 20% had made major adaptations. Furthermore, 32.3% of families (n=99) in While et al's (1996a) study had moved residence for a variety of reasons related to their child's condition. Over a third of these families had some adaptation to their present home with 18 of the 36 families reporting a bathroom or bedroom extension. They concluded, however, that it may be the case that few homes can be easily or adequately adapted for the care of severely disabled children.

Families cannot always afford to move or adapt their homes. Although financial help for home adaptation is available from Local Authorities, via grants for facilities for the disabled, research has shown that families are not always in possession of this information. One fifth of families in Beresford's (1995) study were unaware of the potential help available. For those who do apply for such financial assistance, the process is neither easy nor trouble-free (Beresford et al, 1996). Frequently parents have a lengthy wait to hear the outcome of their application, with 10% of families in Beresford's (1995) study waiting over two years to determine whether their application had been successful. A further period of time waiting for the work to be undertaken is common. Local authorities rarely meet the full costs of structural adaptation so families frequently bear some of the costs involved in addition to re-furnishing and redecorating the new accommodation (Hill, 1994).

2.12.3 Employment

Parental employment and earnings are affected by the demands of caring for a child with a LTI (Stein et al, 1989). Research has indicated that this effect is particularly apparent in relation to mothers who are less likely to be in paid employment when compared with similar mothers in the general population (Baldwin, 1995; Smyth & Robus, 1989). Furthermore, when in employment they are more likely to work part time and are less likely to move towards full time paid employment as their children grow up and their caring role becomes greater (Baldwin, 1985; Beresford et al, 1996). More than a quarter of the mothers in While et al's (1996a) study were in employment mostly on a part time basis. Although mothers not in employment expressed a desire to return to work, 87.4% felt that this would be impossible due to the demands imposed by the LTI.

One parent may sacrifice a career in order to care for the child while the parent in employment frequently may have to give up overtime opportunities in order to be supportive in the home. Periods of acute ill health or hospitalisation may require a parent to take extra time off and can be damaging for career prospects (Hill, 1994). Sometimes the caring burden is

such that the second parent may need to give up work or work part time especially when there is more than one affected child. Such employment constraints may be greatly aggravated for lone parent families (Kagan et al 1998).

Paternal employment and earnings are also affected but to a lesser extent (Beresford et al, 1996), although researchers have been dependent upon mothers' perceptions with views not being directly sought from fathers (While et al, 1996a). While et al (1996a) reported that none of the fathers in their study felt that their child's disorder had caused their unemployment but 38% felt that their attendance at work had been affected. Baldwin (1985) suggested that differences lie in the type of work men do and whether they are engaged in manual or non-manual occupations. The flexibility available to men in non-manual occupations made them less likely to take occasional days off work than manual workers, although their longer-term promotion and career prospects were affected. These constraints directly affect a families' earning capacity. Paternal earnings were found to be 9% lower than the general population in the OPCS (Smyth & Robus, 1989) survey of disabled children with a difference of 7% found in maternal earnings. Such discrepancies were not compensated by the receipt of disability benefits. Both Baldwin (1985) and Smyth & Robus (1989) concluded that all types of families with a disabled child had lower incomes than families in the general population. This evidence suggests that such families have smaller incomes than families in the general population even before starting to meet the additional costs of caring for their child, thus creating a group of families who are significantly worse off when such costs, or as many that can be afforded, are met (Beresford et al, 1996).

When the additional costs of caring are combined with lower incomes there is conflicting evidence to suggest that families' in the caring role have lower living standards when compared with those in the general population (Baldwin 1985; Smyth & Robus, 1989; Beresford, 1995; While et al, 1996a). Three quarters of the entire sample (n=1227) in Beresford's (1995) study reported that they regularly went without, had had to put off paying bills in the

last 12 months or been forced to borrow. Almost three quarters of families expressed a need for more money indicating the likelihood of lower living standards. This finding is consistent with those from the OPCS survey (Smyth & Robus, 1989) in which over half of the families (n=1144) were 'just getting by'. However, this finding was not supported by While et al's study (1996a) who reported only a few families to be having financial difficulties, with most managing financially and satisfied with their standard of living, although sample bias may account for this finding. It may, however, as While et al (1996a) illuminated, be difficult to draw conclusions from studies which do not have a matched control group for comparison and where samples have not been randomly selected. In addition, cross-sectional surveys collecting data at one point in time may not capture the repeated and accumulating costs over time.

2.12.4 Contribution of voluntary organisations

The role of voluntary organisations for children with LTIs has provided an important contribution to the promotion of children's rights and in influencing changes in social policy (Smith, 1989). In addition, it is also notable for the provision of information and emotional support for families (Betz et al, 1990; Cornish et al, 1996). Another significant function has been to provide financial support to health and social services professionals, assisting research as well as practice, although a fall in grants from local and central government has led to a cut back in the expansion programmes of some voluntary organisations (Neale, 1990). While et al (1996a) found that for some well known charitable organisations fundraising was comparatively easy because they provided services for children and because of the emotive nature of the disorders on which they focussed. It can be argued that those organisations serving families caring for children with rare conditions, which are not well known to the general public, are likely to do less well in the competition for funds (Cornish et al, 1996). The focus of service provision for 60% of the organisations (n=147) surveyed by Cornish et al (1996) was diagnosis related. Therefore, families caring for children without a designated diagnosis may be disadvantaged by exclusion from organisations despite

having the same or a greater need for information and support as children with a known disorder.

Evidence shows that voluntary organisations provide considerable practical and informational support and make an enormous difference to parents' lives (Beresford et al, 1996). Bodkin et al (1982) revealed that families of children with cancer received financial help from charitable sources to help towards the costs of travel, special dietary requirements and heating, but severe financial problems were experienced because parents could not be compensated for loss of earnings. In addition, Beresford (1993) compared the effects on families before and after receiving modest utilitarian or financial help from the Family Fund. She revealed that mothers (n=162) perceived fewer care dilemmas and fewer difficulties related to the health and care of their child after receiving help. Further, significant improvements in feelings of well being and in maternal mental and physical health were also noted. The application process in itself may have had some therapeutic value as it involved an in-depth interview with a social worker employed by the Family Fund. This provided an opportunity for the discussion of problems, with the voluntary worker being able to suggest possible solutions and other forms of assistance (Beresford, 1993).

2.12.5 Guidelines for effective interventions

Systematic evaluation of the effects of providing material resources on the lives of families of children with LTIs have not been studied to date. However, Beresford et al (1996) systematically reviewed the research to develop guidelines for effective interventions with families. Primarily they suggested that professionals should appreciate and base their practice on the fact that LTI creates financial pressures and systematically reduces living standards. Effective intervention, therefore, not only requires detailed knowledge of the family's socio-economic situation but also a thorough understanding of the LTI, its effects and likely prognosis. A comprehensive understanding of the types and sources of financial assistance available is required of professionals who should use such knowledge to facilitate a proactive

approach and anticipate families' needs and assist them in obtaining all to which they are entitled. Further, Beresford et al (1996) proposed that families need to be helped with the procedures for applying for benefits and other types of assistance as the process of obtaining help is not always easy and straightforward. In addition, the knowledge of sympathetic, specialist financial advisors is called for. Where necessary families can be referred, not only to assist them in crisis situations but also so that plans for longer-term strategies for managing their family budget can be developed.

2.13 Practical caring

2.13.1 Respite care

All parents feel the need to have a break from looking after their children from time to time. The additional stresses faced by parents caring for children with LTIs frequently increase their need to have someone else take care of their child for short periods. However, the very nature of their child's illness means that it is often more difficult to find informal care to achieve this. Families may have little energy to seek out help for child-related needs when trying to cope with the strains in their everyday lives (Sloper & Turner, 1992). Research has revealed that one of the most frequently reported unmet needs is obtaining some relief from the 24 hour responsibility of caring (Stein & Woolley, 1990; Beresford, 1995; While et al, 1996a). This reflects the burden faced by families in their caring role, their need for practical support, their desire for more respite care and that they are willing to share the burden of caring (NHS Executive, 1998). Evidence from families in While et al's (1996a) study demonstrated that among those who are satisfied with their respite care provision, relief from caring was a significant factor in enabling them to continue caring for their child at home.

Ideal respite care should involve a range of services with the possibility of choice regarding what families need at any particular moment in time (NHS Executive, 1998). Such services should be flexible and offer care in and out of the family home, varying in time span and covering different times of the

day and night. Some children's needs may mean that one to one care is required so that a child may attend a holiday play scheme or go on holiday without his / her family (Simons, 1994). A variety of short-term respite care facilities have been documented in the literature. For disabled children the most commonly available alternative is one which has been developed by many local SSDs in response to the 1989 Children Act. This is family-based respite care where a 'link', 'befriending' or 'host' family offers themselves and their home as a place to take care of the disabled child for a planned period of time. This may range from a few hours, overnight, a weekend or longer (Betts & Meyer, 1993; Beresford et al, 1996). Three quarters of families (n=1227) in Beresford's (1995) study used either this form of respite provision or care provided in statutory (social services) residential centres. It can be argued that this reflects the preferred approach of providing local care in the community. Other forms of short-term respite care can be achieved in the child's own home by qualified nurses or trained carers (ACT & RCPCH, 1997; NHS Executive, 1998) particularly if a child requires terminal care. However, the lack of available resources and expertise precludes all areas from offering this form of support (ACT & RCPCH, 1997).

An appropriate range of services is not uniformly available to all families. This is particularly apparent when considering the needs of the family caring for a profoundly disabled child; a child with complex health care needs (Betts & Meyer, 1993); or for children who need any form of nursing or symptom management during periods of respite care (ACT & RCPCH, 1997). It can be argued that the greater the degree of the child's disability or illness, the less appropriate the statutory respite care is for families (Betts & Meyer, 1993). Few would dispute the view that an acute hospital children's ward is an inappropriate venue for respite care (Department of Health, 1991), although, it is recognised that for some families the hospital provides a sense of security, as care is continued by a team with whom they are familiar (Goldman et al, 1990). However, what is less well recognised is that the environment of care centres designed for children with learning disabilities is totally unsuitable for a non-cognitively impaired child with complex physical problems (Betts & Meyer, 1993; ACT & RCPCH, 1997). Joint Working Party

evidence in the public domain for more than 10 years recommended that it should be the duty of health authorities rather than social services to provide respite care for this group of families (NAHA, 1988).

Volunteers who assist with care in the family home are also valued by families. Working party evidence (ACT & RCPCH, 1997) revealed that successful services have matched carers with individual children and their families so that they can be trained to undertake specific tasks (for example physiotherapy, suctioning and tube feeding). The voluntary sector in recognising the shortfall in suitable statutory provision has developed a highly specialised network for respite care and support for children with LTIs. The growth in the number of children's hospices (Thompson, 1998; Farrell & Allen, 1998) is evidence of this, as is the development of organisations offering domiciliary care (Cleary, 1990); self-help groups (Lavery, 1990) as well as innovative support mechanisms initiated at local level (NHS Executive, 1998).

Provision of appropriate respite care is patchy and many areas are served less well than others. Large numbers of families have not been offered or are unaware of the availability of such services (ACT & RCPCH, 1997). Almost a quarter of families interviewed by While et al (1996a) were unaware that help in the form of respite care was available to them. The lack of uniformity of statutory services has been exaggerated by the purchaser / provider split created by the 1990 NHS and the Community Care Act. Statutory services have been able to purchase respite services, for a population of children with LTI whose numbers within any one geographical area will only ever be small, which they have argued could not be effectively provided within their own boundaries. This means that families often have to travel great distances from their home in order to benefit from respite provision. For example, Dominica and Hunt (1993) reported that more than half the families receiving care in Helen House travelled over 50 miles, while 16% travelled more than 100 miles. Families (n=25) in Stein et al's (1989) study expressed a need for respite care local to their own homes. Conversely, working party evidence (ACT & RCPCH, 1997) suggested that families are willing to travel to an

acceptable service, if help with transport costs is provided. Nevertheless, this same working party recommended that NHS trusts should look at the location of existing children's hospices and other appropriate facilities and cooperate and coordinate arrangements for respite care with neighbouring providers as necessary (ACT & RCPCH, 1997).

A number of studies have highlighted the degree of unmet respite care needs of families (Stein et al, 1989; Soutter et al, 1994; Duncan & O'Flynn, 1995; While et al, 1996a). Indeed, Stein et al (1989) reported that 60% of their sample (n=25) had such difficulty in finding child-minders, particularly if their child had a very serious illness (example cited epilepsy), that their lives were severely limited, a finding substantiated by Sloper & Turner (1992) who found that almost half of their respondents (n=107) expressed a need for babysitting and child minding.

A range of difficulties with the provision of respite care has been highlighted. Families are particularly dissatisfied with the amount of care available (NHS Executive, 1998) and the fact that it is not available when they have needed it most, for example, at weekends and during school holidays (Beresford, 1994). A minority of children (n=16) in While et al's (1996a) study had had a holiday provided for them by a voluntary organisation in the past year. While the length of respite care ranged markedly from one to 14 nights only one family was not satisfied with the arrangements. Such holidays, while a welcome break for the child and family, constitute only a small part of school vacation time.

As the child grows older and bigger parents' need for a break from caring tends to increase. Not only do parents find the caring role very demanding but informal sources of support for example from extended family members and friends tend to dwindle over time, causing parents to look for help from more formal sources (Brown & Hepple, 1989). The need for improved facilities for teenagers has also been recommended (NHS Executive, 1998). The transitional care needs of older teenagers and young adults require specific attention because they have discrete and different needs which are

not being met by current service provision (House of Commons, 1997). They have a need for appropriate leisure and recreation facilities, appropriate symptom management, and greater privacy and independence (ACT & RCPCH, 1997). Although some hospice facilities are flexible at the upper age limit to allow for children who live beyond their life expectancy it is likely that increasing numbers will overwhelm the facilities. The working party evidence regarding children's palliative care services recommended that to fill this gap in service provision and ease the transition between paediatric and adult services, close liaison with both adult and children's services was essential and would enhance the development of services for young people with LTI (ACT & RCPCH, 1997).

Difficulties with the recruitment of 'host' families to participate in SSD 'link' or 'befriending' schemes have been reported particularly for children with complex health care needs (Stein & Woolley, 1990), while other research has reported access difficulties for immobile children using wheelchairs (While et al, 1996a) or where children require other daily living aids. The training of host families to undertake special health care tasks is not without difficulty as issues concerning indemnity must be addressed (Noyes, 1996 personal communication).

Families caring for children with very complex health care needs which demand 24 hour care and management or terminal care undoubtedly need regular, planned short term breaks as well as help during times of crisis (NHS Executive, 1998). A number of studies have shown that families believe using respite care services is a sign that they are not coping (While et al, 1996a) or that the child him / herself will not be able to deal with the separation (Beresford, 1994). Evidence from the pilot project programme for children with LTI (NHS Executive, 1998) concluded that a reluctance to use hospice facilities may be due to the way in which the concept of respite care has been introduced to the family. Family concerns may be related to the misconception perceived from the adult hospice movement that a children's hospice is associated solely with death and dying (Davies, 1998). Further, it may mark a milestone in the acceptance by the family of the fragility of the

child's life expectancy. This group of families are likely to have experienced considerable family disruption due to lengthy stays in hospital and as a consequence they often express a preference for home based respite care (Soutter et al, 1994; While et al, 1996a). Families of young children (under five years of age) seem to prefer respite in the home (NHS Executive, 1998).

Other families have found tremendous help, support and comfort from services provided under the umbrella of the children's hospice philosophy (Stein & Woolley, 1990). Families in While et al's (1996a) study appreciated the home from home environment, the ability to continue participating in their child's care and the continuity of contact between admissions to a children's hospice. Further, evidence from the pilot project programme for children with LTIs (NHS Exec, 1998) concluded that families valued the philosophy which guided the holistic caring approach, high standard of facilities offered in a warm friendly atmosphere, flexibility of staff, high nursing staff to child ratio and the mutual support derived from contact with other families using the hospice.

In their study of 25 families attending Helen House children's hospice Stein et al (1989) found a number of common reasons why families sought hospice care. Interestingly, the most common theme was not for respite care per se but the desire for care in a non-hospital environment where they were able to relax in a homely atmosphere which allowed time for talking and for emotional support. Secondly, families desired medical care which emphasised symptom control and relief rather than active intervention. Thirdly, families expressed a need for respite care as a reason for using the hospice.

2.13.2 Assistance with daily life

A number of factors have been highlighted in the research literature which have suggested that having a child with a LTI increases caring and household tasks substantially (Quine & Pahl, 1989; Beresford, 1995). A child's special care needs, such as physiotherapy, are frequently time

consuming and often encroach on family activities. Additionally, disabled children remain dependent on others to meet their self-care needs for much longer than non-disabled children, so problems associated with the child's condition for example, eating and behaviour problems, and incontinence, may increase the caring and housework burden (Beresford et al, 1996). Moreover, parents often find it difficult to leave their child unattended even for short periods of time (Stein & Woolley, 1990). Thus, many parents find that they have very little time either for themselves or to do housework.

Parents place little importance on the need for help with household chores. However, Beresford's (1995) national survey (n=1227) found that 40% of parents reported needing help with the day to day care of their child and with chores around the house. A positive correlation has been demonstrated between the levels of stress reported by mothers and the amount of extra work required in the home as a result of their child's illness (Quine & Pahl, 1991). Thus, there is a need for the provision of practical assistance to minimise the burden of both caring for the child and with undertaking usual domestic duties (Baldwin & Carlisle, 1994).

Parents, however, differ in their preference for the kind of domiciliary support which they would like to receive. Some families prefer assistance with household chores, while others would like help with meeting their child's self care needs (Beresford et al, 1996). Although an unmet need for domiciliary support was identified by nearly half the families in While et al's (1996a) study only four families expressed a need for a home help. While this highlights the perceived unimportance placed on household chores it does not support Beresford et al's (1996) view above, as interestingly, 30 families in While et al's (1996a) study expressed a need for a home-based service which would help them with in their daily caring activities. Nevertheless, the need for assistance in the home, whether it be in a caring capacity or with housework, helps parents to have greater quality time, both with their child and the rest of their family (Beresford, 1994). Such quality time plays an important role in maintaining positive family relationships which contribute to parents ability to continue in their caring role.

2.13.3 Assistance with daily treatments

Parents caring for children with LTIs have a need to acquire skills which exceed typical parenting skills (Beresford et al, 1996). Skills such as to assist their child's development, enable them to meet their child's health care needs and help them deal with particular problems such as sleep disturbance, communication or behaviour difficulties. Half of the families (n=42) interviewed by Stein and Woolley (1990) reported major difficulties with their child's mobility, toileting, communication and speech, while a third of all the children studied had persistent problems with sleeping. Studies, particularly those involving disabled children, have shown that the need to acquire these extra skills has remained unmet or has only been partially met by services (Sloper & Turner, 1992; Quine & Pahl, 1989).

The experience of taking care of their child day by day confers expertise on parents (Dominica, 1990a; Jerrett, 1994), but families have a need for guidance with practical health care interventions. For example, Norman and Bennett (1986) found that parents believed they had no points of reference to assist them in making decisions, especially with technical procedures such as giving oxygen and administering analgesia by injection. Kendrick (1993) argued that formal education is essential if children and their parents are to carry out complicated procedures like the administration of intravenous drugs at home. Once in possession of these skills, families also need on going support and confirmation that they are giving the correct care (Norman & Bennett, 1986). This, as Whyte (1992) suggested, requires the nurse to share the illness trajectory with families and to assist the family members to experience it together.

There is an understandable reluctance on the part of parents to pass on the responsibility of care to others (Whyte, 1992; While et al, 1996b). The extra needs of the child are not trivial, and the health care skills acquired by parents over a period of time cannot be readily relinquished to leave the child in unskilled hands (Whyte, 1992). Evidence shows that a one to one arrangement for care in the home, whether it be for respite or to assist the

family with practical health care tasks is ideal. The initial reluctance on the part of the family to leave a child requiring large amounts of health care may be overcome by providing continuity with the same nurse or carer (NHS Executive, 1998).

2.14 Educational issues

2.14.1 Collaboration between education and health services

Children and their families living with LTI need access to a wide range of services across all the statutory and voluntary organisations (Burne, 1988). Very few studies in the literature have focussed solely on childhood LTI and its relationship with education services. When a child becomes seriously ill their health needs supersede all others. However, one of the main normalising factors in a child's life is the provision of appropriate schooling (Simons, 1994). As an experienced head-teacher, Jeffrey (1990) disputed the view that providing education for a child with a limited life span was a fruitless task and that concentration on lessons, homework and academia a wasted effort and unkind to the child. Essentially, education represents normality, and normal expectations are reassuring for the child with a LTI (Jeffrey, 1990; Simons, 1994; Trapp, 1994).

The hopes and aspirations of three families concerning their children's education have been analysed by Closs and Burnett (1995). These families participated in a conference which constituted the preliminary investigations of a national survey of policies and provision for the education of children with serious medical conditions in Scotland. They acknowledged that the views of such a small number of families should not be considered representative. Nevertheless, the themes which emerged from their analysis were considered to be relevant to families caring for children with a LTI and to those professionals from a variety of agencies involved with such families.

Education should be accessible to all children whatever their condition or life expectancy (Lavelle, 1994). It should be child-centred, flexible and should

adapt to the child. A child's education is important to the family. In the words of one parent in Closs and Burnett's (1995) study: "it (education) should be where the child is and what they can learn and what they want to do at any time" (p390). Lavelle (1994) argued that there are two principal reasons for a child with a LTI to continue with formal education. Firstly, however long or short their life may be, children have the right to the opportunity to developing their potential abilities and enjoy the enrichment which education affords. Closs and Burnett (1995) presented evidence which suggested that families believed education should offer an opportunity for their child to be successful, fulfil their potential and provide intellectual satisfaction. Secondly, going to school, or indeed returning after some time away, establishes a regular pattern of life for the child as well as contact with their peer group. Although this may present difficulties, while parents hope for the development of peer friendships or companionship it was distressing for families in Closs and Burnett's study (1995) when their child experienced rejection or teasing. In addition, education for a child with a degenerative condition offers an opportunity to thrive intellectually despite physical limitations. This belief is supported by the views of one family, reported by Closs and Burnett (1995), who argued that the pursuit of knowledge and understanding was a pleasure for their children with CF. Further, they viewed schooling as a distraction from aspects of their illness which they found distressing. When a child's daily routine is comfortable and familiar, family life and the stresses and strains of living with LTI are easier to cope with (Eiser, 1990).

Lavelle (1994) has asserted that all that is necessary in securing a continuing educational placement for the child is to define the child's needs and then match the child to a service which can best meet these needs. In reality, the solution is not always readily available or accessible. The process and difficulties experienced by children when re-integrating into school life may be underestimated by medical staff (Eiser, 1990). Parents too, often have reservations about the suitability of the main-stream school environment. The need to inform the teacher about their child's illness often conflicts with their desire for their child to be treated as much like others as possible (Eiser, 1993). A sense of normality can be maintained while receiving treatment in

hospital by continuing with school work with the help of the hospital teacher. Friends and teachers when encouraged to visit during this time, maintain a contact with the school and facilitates the transition back to school after discharge (Peace et al, 1992).

Nearly three quarters (73%) of parents of children with a diagnosis of potential anaphylactic reactions to food who required access to immediate treatment with epinephrine and supported in one health authority (n=41) participated in a study to assess the effectiveness of a training programme. This aimed to inform school staff about a child's treatment and to reduce both parental and school staff anxiety (Vickers et al, 1997). Main parental concerns were that their child should be taught in a safe environment while maintaining a normal a lifestyle as possible. Parents reported difficulty and found it stressful when liaising directly with school staff and often felt that their situation was not being taken seriously, a view supported by Eiser (1990) who argued that parents often worry about teachers not making appropriate allowances for a child who feels unwell, or being incompetent in an emergency situation. Concerns voiced by school staff in Vickers et al's (1997) study revolved around a lack of knowledge about the child's condition and about being able to recognise and respond in an emergency. The training programme discussed by Vickers et al (1997) entailed both written and practical demonstrations of the management of the child's situation by health professionals. The study found the programme to be reported as helpful by all parties involved, but interestingly, showed that all anxieties could not be totally eradicated, although fewer school staff as well as fewer parents were reported to have concerns after the intervention programme than before, although statistical significance was not achieved. Nevertheless, this study has demonstrated that children with LTI can continue in main stream schooling, although the support required is often complex, time consuming and close liaison between clinicians, schools, families and those responsible for policy making is absolute. However, in current service provision this study highlights the exception rather than the rule. Although most schools have a designated school nurse, she / he may have neither the time nor the skills to give significant support to children with LTI, this therefore leaves a gap in

service provision which parents often fill (ACT & RCPCH, 1997).

Difficulties at school may arise partly out of teachers' lack of experience of LTI in their personal lives and what knowledge they do possess may be inappropriate, sparse, or outdated in relation to children. Personal experiences may, argued Eiser (1993), be of only limited use in helping teachers to know how to deal with sick children in the classroom, or, may even be detrimental to the child or healthy peers if the teacher has inappropriately negative expectations of the child's illness. There are deficits in teachers' professional training regarding the effects of illness on children's learning, about common conditions and even about working with parents of sick children, thus they start from a disadvantaged view point (Closs & Burnett, 1995). While hospital and special education teachers have the opportunity to learn 'on the job', for teachers in main-stream schooling their first experience of LTI may be when a child appears in their classroom. However, the shift in emphasis from special to main-stream schooling for children with special educational needs (NHS Executive, 1996) and the health services shift in emphasis from hospital to home care (House of Commons, 1997) means that main-stream teachers are likely to be faced more frequently with LT and terminally ill children. Thus, there is an urgent need for research to evaluate the role of medical and nursing staff in schools (NHS Executive, 1996) and the benefits of interagency collaboration and liaison in reducing professional and parental anxiety. It is frequently financially viable for tertiary centres to employ specialist liaison nurses who, as one component of their role, can inform schools about a child's illness as well as offer advice regarding the impact on school life (Curnick, 1990; Hunt, 1995; ACT & RCPCH, 1997). However, this is frequently not possible for smaller or less well funded establishments. A lack of liaison nursing increases the opportunity for misunderstanding and communication difficulties between hospital, home and school (Eiser, 1993).

2.14.2 Acquisition of skills

Special schools are usually the most appropriate placement for children with

profound physical and learning disabilities as they offer nursing and therapy services within a school environment (ACT & RCPCH, 1997) where the teaching programme balances the child's individual physical, developmental and intellectual needs (Lavelle, 1994). It may be more of a challenge for teachers to provide support to a dying child's peers throughout the later stages of the illness and into the bereavement period when children use non-verbal methods of communication or have reduced cognitive abilities. However, the 'parental grapevine' and the sense of security and community engendered by such environments is an enormous source of support to parents (Soutter et al, 1994; Lavelle, 1994; ACT & RCPCH, 1997). Parents in Beresford's (1994) study reported that one of the greatest sources of stress concerned conflict with education professionals at all levels of the service. The assessment process of the child's special educational needs (Education Act 1993), negotiating with local education authorities and dissatisfaction with the child's educational placement were areas considered to be distressing and exhausting.

School is viewed by some parents as a form of 'legitimate' respite care. Some special schools organise respite care packages for children in their care (Stein & Woolley, 1990). Evidence from Beresford's study (1994) suggested that school is an acceptable means of obtaining some relief from the caring burden which also benefits the child. In particular, she described the views of parents whose children had only recently started school, and how the school day enabled them to resume activities such as shopping in town which they had previously had to forego. Eiser (1993) also noted how a child's return to school may be important for other members of the family, because it allowed parents to rediscover their own lives. For some parents it is important that they are able to return to work as soon as possible to alleviate financial difficulties.

Parents in Beresford's (1994) study who expressed satisfaction with their child's schooling did so because they perceived others were interested in their child and were doing their best to help their child. This afforded them both a feeling of being supported and relief from not being alone in their

struggle to give their child the best prospect in life. Parents enjoy witnessing their child's progress at school, "whether in academic, social or life skills" (Beresford, 1994 p. 41). One mother was overjoyed at witnessing her son, dressed in uniform, sitting at a desk in school, something which previously she had never been able to imagine (Beresford, 1994).

A realistic assessment of the child's needs can only be made when medical, social and educational information is collated together by the professionals involved (Lavelle, 1994). Teachers can use their unique teaching and management skills to help the sick child enjoy school as well as learn as effectively as possible. They can be effective in enabling education to act as a marker of a dying child's existence and significance. The posthumous award of degrees to two young people held great significance for parents not only because their children had earned them but also because it told the world of their children's existence and success (Closs & Burnett, 1995). Insightful teachers can enable a child to explore his feelings about life and death perhaps in the form of a reflective autobiography or allow the child to satisfy his thirst for answers to questions. Parents often have an understandable wish for their child to see and do everything before they die. Teachers can help to moderate this by channeling a child's energy into a project involving the whole family, equally satisfying but less exhausting (Closs & Burnett 1995).

2.15 Community Children's Nursing

2.15.1 Introduction

Children under 18 years of age comprise nearly a quarter of the population (Audit Commission, 1994) and are major consumers of health care (NHS Executive, 1996). The need for home care for sick and disabled children has been recognised since the 1950s as an important alternative to traditional hospital care to avoid the deleterious effects of hospitalisation revealed by Bowlby (1953) in an examination of the effects of separation on mothers and children. The special skills required by nurses to care for sick children at

home have recently received acknowledgement in the formal Community Children's Nursing (CCN) qualification (UKCC, 1994), coupled with recommendations of recent government publications (NHS Executive 1996; House of Commons, 1997) has led to the development of services which have thus far been slow and sporadic. In addition, these recommendations have fuelled the debate concerning the diversity in formation of CCN services and the need to define and give structure to principal emerging models. Factors for consideration in future developments are issues such as: focus (specialist versus generalist nursing expertise); location (hospital versus community based); accountability (hospital versus community trust versus integrated child health service); and funding source (charitable organisations versus central government versus NHS trust) and are presently being discussed in the literature (Winter & Teare, 1997; Neil & Muir, 1997; Evans & Thompson, 1998; Kelly, 1998; Eaton & Thomas, 1998; Proctor et al, 1999; While & Dyson, In press).

2.15.2 Models of home care

The lack of a systematic approach in the development of CCN services is evident (House of Commons, 1997; While & Dyson, In press). Local circumstances coupled with the enthusiasm of children's nurses have, in many instances, been the driving force behind the development of a CCN service (Dryden, 1986) and this has contributed to the diverse pattern of provision. Therefore, a major difficulty for the 50% of Trusts who have no CCN service (House of Commons, 1997) is the lack of an accepted model on which to base future developments. While and Dyson's (In press) recent survey of the attributes of home care found evidence to suggest that two models dominate present provision of children's home care: 1) the hospital outreach model which has strong links with the acute hospital service and 2) the community model with its firm associations with the primary health care team (PHCT). Funding for services comes from a variety of sources including community and acute NHS Trusts and charities (Neil & Muir, 1997), but is often problematic (Proctor et al, 1999) and the source of funding has implications for practice. While and Dyson's (In press) correlation

analysis revealed that Community Trust funded teams more frequently derived their caseload from a defined geographical area and were more likely to receive referrals from PHCT members and accept direct referrals from families. Hospital Trust funded teams, however, were more likely to employ staff holding degrees or other higher qualifications, with nurses deployed in specialist rather than generalist roles, and with the hospital service being the main source of referrals. Interestingly, Community Trust funded teams were found to employ more nurses holding specialist community nursing qualifications and who worked more extensive hours in line with their PHCT colleagues in district nursing.

A developmental model for CCN practice and education has recently been proposed by Proctor et al in a report commissioned by the ENB for England and Wales into professional education concerning preparation for the developing role of the CCN (Proctor et al, 1999). This research combined findings from a structured national postal survey aimed at characterising models of CCN services, with semi-structured interviews with a purposive sample of professionals (n=41) from six sites in the UK who had demonstrated enthusiasm for collaborating in the research in the postal survey. Their sampling procedures ensured a balance in type of service according to Trust characteristics (i.e. community, acute, combined, integrated) and a geographical spread throughout England. Semi-structured interviews were undertaken with families and children (n=38) selected to participate on the recommendation of CCN service managers (professional interviewees) to explore their needs and experiences with professionals. In addition, three focus groups were conducted to aid exploration of emerging themes from the research and focused on: availability of services from a voluntary organisation perspective, multi-professional working and education for CCNs. Evidence was presented for the development of a process model which was diverse, flexible and responsive to the needs of families. Seventeen guiding principles were proposed which were based heavily on standards from the health visiting domain and emphasising the importance of a service grounded in family-centred practice. Each principle reflected either end of a disease prevention - health promotion continuum. Moreover, they

proposed from thematic analysis of family interview and focus group data that CCN services provided care in the home on three levels: 1) task orientated care by hospital based children's nurses; 2) task orientated care by community based children's nurses; 3) family-centred care embracing community perspectives in the development of supportive partnership relationships with families.

The literature provided numerous accounts of generic service development (Dryden, 1986; Dryden, 1989a Dryden, 1989b; Whiting, 1989; Fradd, 1990; While, 1991; Gow & Ridgway, 1993; Sidey, 1995) as well as descriptive studies of parents' and professionals' views (Lessing & Tatman, 1991; Tatman et al, 1992; While, 1992; Jennings, 1994; Nursing Standard Reports, 1996; Gow & Campbell, 1996). However, there is a paucity of robust controlled or evaluative research investigating the strengths and weaknesses of the different models of home care for children (House of Commons, 1997; While & Dyson, In press) and the clinical effectiveness of CCN practice (Proctor et al, 1999). Indeed, part of the Government (Department of Health, 1997) response to the recommendations made by the House of Commons Health Committee (1997) recognised that, as a relatively new form of service provision, research into the effectiveness of differing models of community children's nursing is urgently required.

A number of surveys of CCN teams in England have been undertaken since 1988 (Whiting, 1988; Tatman & Woodruffe, 1993; RCN, 1996; While & Dyson, In press). These show that there has been an increase in home care services for children over the last 10 years. However, it is still a serious cause for concern that, presently, CCN services are purchased by only 50% of health authorities and that only 10% of children in England have access to a nursing service which spans a 24 hour period (House of Commons, 1997). While and Dyson (In press) revealed that although all but three teams (n=109) surveyed in 1997 provided a Monday to Friday 9am to 5pm service only 32.4% of teams worked during weekends and Bank holidays, with a very small minority (5.6%) providing a service to children in their homes at night. The reason for this is probably reflected in the size of the CCN teams. A

substantial number of teams, despite Department of Health (NHS Executive, 1996) recommendations that sufficient staff to provide a 24 hour service are required, are maintained on a minimal staffing level where annual leave, sickness and maternity leave can easily jeopardise effective service delivery (While & Dyson, In press). Although While and Dyson's (In press) study showed an increase in the number of whole time equivalent (WTE) nurses to a median of three, when comparison is made with the figure of 2.5 WTE reported by Tatman and Woodruffe (1993), such a small positive trend does little to contribute to achieving the significant expansion of CCN services which is necessary if children are to receive a comparable service to adults. A 24 hour home nursing service led by qualified district nurses has been available to all adults requiring nursing interventions in their own homes for many years. Not only does this serve to highlight the disparity between adult and children's services but also reflects the perceived unimportance of the special and particular needs of sick and disabled children. Families caring for a child with a LTI need and deserve a comparable service as a matter of principle (House of Commons, 1997). It is disappointing to discover that a minority of teams in While and Dyson's (In press) survey comprised staff of whom more than half were not trained in the care of sick children and almost a third (29.2%) of the teams had no member with a community nursing qualification. Interestingly, Proctor et al's (1999) research excluded Trusts with teams of two WTE and below members of staff. While they acknowledged that their sample appeared skewed in the direction of teams with more than 10 nurses, all six of their study sites had teams greater than the median of three WTE nurses revealed by While and Dyson (In press).

2.15.3 Skills and training

Insufficient attention has been given to the need to provide training for nurses to deal with the specific needs of sick and disabled children in home care. Evidence presented by Burr to the House of Commons Health Committee (Burr, 1997) stated that there has been a dramatic rise over the last five years in educational opportunities for those wishing to nurse sick and disabled children. Although a number of educational institutions have been

approved to provide a post registration programme for CCNs and "despite an excess of suitable candidates, some programmes are not available because education consortia have failed to commission places" (House of Commons, 1997 p. lxii). Proctor et al, (1999) recommended that it should be a requirement for all nurses caring for sick and disabled children in the community to hold a CCN qualification. Nevertheless, factors such as a paucity of funding sources, finding appropriate placements as well as appropriately qualified practitioners able to supervise CCN students are challenges which require solutions before CCN services can be systematically developed for all sick and disabled children at home (Neil & Muir, 1997).

2.16 Parental participation

Most parents are willing and capable of participating in their child's care in hospital although the extent of their involvement ranges substantially (Cleary et al, 1986; Sainsbury et al, 1986; Coyne, 1995). Darbyshire (1994), in his phenomenological study exploring the lived experiences of parents (n=30) resident in hospital with their sick child, revealed that some parents felt expected to perform too much of their child's care without enough help and support. In her critique of the literature, Coyne (1995) highlighted the apparent confusion regarding the expectations of parents, in that a lack of information from, or negotiation with, professionals prevented them from participating as they would have liked. At one end of the spectrum of participation some parents may prefer to avoid additional stress and defer care to professionals altogether. Moreover, Coyne (1995) revealed that the degree of parental involvement may in fact be at the discretion of children's nurses, and that this confusion is compounded by a lack of agreement within the profession as to the format and extent of the process of parental participation (Dearmun, 1992). This process may be more of an informal "unspoken arrangement" (Darbyshire, 1994 p.203) than an explicit, evidence-based nursing practice.

Parents caring for a child with a LTI at home are not afforded the luxury of

being able to defer care to professionals, if they should wish to and increasingly, are carrying out highly technical nursing care in their own homes (Kirk, 1998). Families (n=38) interviewed by Proctor et al, (1999) were revealed as experts in their child's care and daily activities and any early parental concerns about managing complex technological care were dissipated quickly. The non-participant observational study, evaluating a care by parent scheme in one hospital ward (Cleary et al, 1986), suggested that a potential benefit of sharing care with parents would endow parents with greater knowledge and skills, enabling them to be able to cope better at home during future episodes of ill health. It is thus important for the CCN to develop a body of knowledge and understanding of the wishes and needs of families rather than rely on possibly mis-directed or misplaced assumptions when planning caring interventions with families (Coyne, 1995). This knowledge is particularly pertinent for CCNs to prepare and assist the family in attaining or maintaining control of their situation and enabling their participatory role at home. One of Proctor et al's (1999) guiding principles stated that a CCN provided a higher level of service by "maintaining or improving the quality of life of the family, rather than focusing on medical needs" (p.110).

2.17 Partnership with parents

The quality of the relationship which develops between a family and nurse determines the effectiveness of the help given and received. The ideal relationship to effect help is one based on partnership (Davis, 1993), rather than a dictatorial one in which the professional exerts expert power to make decisions and take control of the child and family's situation (Dale, 1996). Striving for the ideal successful partnership is not without difficulty as nurses need an explicit understanding of the relationship in which they are engaged as well as the ability to negotiate with the family to find out their expectations (Casey, 1993; Davis, 1993; Dale, 1996). Davis (1993) outlined a number of factors which constitute a successful partnership. The nurse and family should be committed to working closely together with explicitly agreed common goals. In addition, although parental and professional roles, values,

worries and training are different, each partner should respect the expertise and skills of the other, and acknowledge the equal status and complementary nature of the attributes which each brings to the relationship, although, as Casey (1993) pointed out, a partnership does not require that tasks are equally distributed.

Another important aspect in any relationship concerns the process of negotiation. A key element in Dale's (1996) Negotiating Model is the principle that the process of negotiation has two possible outcomes: "a shared understanding and consensus or a lack of shared understanding and dissent" (p.15). In addition, dialogue between the nurse and parent is dynamic and subject to a feed back mechanism and that a relationship may be temporarily or permanently unable to function as a partnership if strategies to resolve disagreements and reach consensus are not developed. Davis (1993) has argued that conflict may not always be recognised especially when the relationship is authoritarian. Basing a relationship on negotiation reduces the likelihood of conflict and further enhances mutual respect, where ideas, feelings and information can be shared openly and honestly even when the information imparted is painful.

Skilled communication involving easy, two-way exchange of information, understood by both parties is another principle which underpins a successful relationship (Dale, 1996). From the nurse's point of view this involves: providing an appropriate setting and circumstances in which the family can give clear information; listening carefully to what the family says; clarifying the information to make sure that it has been understood; and then responding appropriately (Davis, 1993). Flexibility in the relationship is also an essential characteristic in any partnership. For the nurse this must include being able to adapt to parents' emotional highs and lows, their evolving coping strategies and the development of alternative sources of support (Casey, 1993; Davis, 1993). Nevertheless, Cox and Parish's (1989) study examining two Barnardo's projects supporting children with learning difficulties revealed that the attitudes which parents and professionals had to their perceived roles was crucial and that for successful partnerships to be

effected in their study area a change in attitudes was necessary. Parents required confidence, skills and resources while professionals needed support in relinquishing control and their authoritarian approach. To effect such change, appropriate training and education for parents and professionals was essential.

2.18 Empowerment

The process of empowerment assists those who may be disadvantaged to take up a more powerful and effective position in their own lives and in their relationships with others (Dale, 1996). For professionals, empowering parents is a process in which a family's ability to meet their own needs is recognised, promoted and enhanced to help them be more assertive, facilitate them to have more power and control over decision-making processes in the management of their child's care and treatment, and when necessary assist them to exert their legal rights (Gibson, 1995; Dale, 1996). The processes of enabling and advocacy are two methods which serve to empower parents. Dale (1996) recommended a number of ways in which professionals can use their skills and resources to assist parents to become more confident, assertive and effective and thus enable them to develop and utilise their own personal resources, although, Gibson's (1995) fieldwork study of twelve mothers revealed that support from professionals was a minority component in the process of empowerment, with intra-personal factors such as mothers' values, beliefs, determination and past experiences contributing the larger influence. Conversely, the principal factor in an advocacy role is the process of acting on behalf of the parent and in the representing of their views or perspective by the professional. Dale (1996) has argued that the nurse should distinguish between these processes and negotiate with the parents which process would be more useful for them. However, in an advocacy role there is a greater likelihood that the professional may be pulled into a situation where (s)he is caught between the conflicting interests of parents and employer. Nevertheless, the process of advocacy may be required in certain circumstances when the parents are unable to communicate for themselves, when expert representation is

needed, for example, in a legal dispute or when the parents have been actively dis-empowered by other professionals (Dale, 1996). Valentine's (1998) qualitative study which explored the concept of family empowerment with a theoretical sample of children's nurses (n=10) concluded that a shift away from medically orientated care towards a model of care based on partnership with families was necessary if true family empowerment was to be realised.

A number of studies have illustrated the importance of working in partnership and empowering families caring for children with LTIs as well as highlighting the detrimental effects that a lack of such practices creates (Krulik, 1980; Cox & Parish, 1989; McConachie, 1994; Jerrett, 1994; Soutter et al, 1994; Baine et al, 1995; Duncan & O'Flynn, 1995; Appleton et al; 1997; Gravelle, 1997; Gibson, 1995; Valentine, 1998). Casey (1988) developed and implemented the Partnership Model of Nursing care specifically for use with sick children and their families in hospital. This was based on the philosophy that: "the care of children, well or sick is best carried out by their families with varying degrees of help from suitably qualified members of the health care team whenever necessary" (p.8). However, for the model to be utilised successfully, the commitment of nurses to develop an active partnership with families is paramount (Farrell, 1992).

2.19 Keyworkers for families

A notable recommendation of many research studies and working party evidence is the need for a key worker. The role of such a professional is to serve as an initial point of reference to guide and assist families and help coordinate and liaise between the myriad of different agencies which provide support for them (NAHA, 1988; Woolley et al, 1991; Sloper & Turner, 1992; Soutter et al, 1994; Beresford, 1995; Duncan & O'Flynn, 1995; While et al, 1996a; ACT & RCPCH, 1997; NHS executive, 1998; Proctor et al, 1999). The appointment of such a professional has been recommended by policy makers for many years (Department of Health & Social Security, 1976), although, disappointingly, research continues to reveal that, in general, only

a minority of families have access to someone who acts in this role. Woolley et al (1991) found that almost three quarters (n=34) of their respondents (n=45) were able to identify one or more professionals as their cornerstone carers. Sloper and Turner (1992) reported that 55% of their sample (n=105) had a key worker, with While et al (1996a) revealing that less than a third (n=28) of children had a nominated professional coordinating their care. Disappointingly, Less than 25% of families in Beresford's (1995) national survey reported having a key worker.

Woolley et al (1991) in their study of families (n=45) prior to receiving hospice care revealed seven components of care valued by parents who demanded a wide range of knowledge and skills and a flexible and honest approach from their cornerstone carers. Qualities included: being available with mutually agreed periods of contact; unobtrusive support; good understanding of the disorder, treatments and prognosis; knowledge of available services, resources and benefits; continuity of caring professionals throughout the illness trajectory and beyond into the period of bereavement; time to listen and time to talk and a sense of humour. The goal of every health professional should be to meet these aspects of care appreciated by parents. Children have a right to such standards of care (Children Act, 1989). However, it is an unrealistic task for the lone professional (Halliday, 1990) and confirms the need for a team or multi-professional approach to care (Woolley et al, 1991; Proctor et al, 1999) for effective service delivery and to enrich the quality of care for families (Norman & Bennett, 1986).

2.20 Multi-professional working

Effective service provision for children is impeded by deficiencies in liaison and co-operation between health, social and education services (House of Commons, 1997). Thoughtful co-ordination between primary, secondary and tertiary caring services is essential (Kelly, 1998; O'Neill & Rodway, 1998) as 10 - 20 professionals might need to be involved with families of children with profound disabilities and complex disorders (Sloper & Turner, 1992). Studies have confirmed the need for improved communications (Nursing Standard

Reports, 1996) and greater liaison between those involved in care (Gow & Campbell, 1996; Proctor et al, 1999). A key factor effecting collaboration is for all those involved in care to have a clear understanding of the roles and responsibilities of other team members (O'Neill & Rodway, 1998; Proctor et el, 1999). Such an understanding encourages mutual respect for the contribution made by each team member (Proctor et al, 1999). Proctor et al (1999) also revealed that formal systems for recording and sharing information were possible but were perceived as impossibly time consuming and that personal face to face contact was valued more highly by the participants in their study. The roles and responsibilities of many CCN services in their early stages of development are presently poorly defined (Charlton & Macaulay, 1993) and require careful 'public relations', with CCNs taking every opportunity to discuss their role with the PHCT and secondary health services (Gow & Campbell, 1996). Recent literature is, however, attempting to rectify this situation (Kelly, 1998; Proctor et al, 1999; While & Dyson, In press).

2.21 Summary

Scientific advances and the changing health care needs of children with LTIs coupled with the shift in emphasis from hospital to home care means that it is now common place for families to manage the complexities of their child's care at home. Despite recent policy changes within health, education and social services and recommendations from many government reports families caring for sick and disabled children continue to have a range of unmet needs and often find themselves unsupported in their caring role. Research has identified families to have informational, practical, emotional and financial needs which must be addressed if families are to feel fully supported in their caring role.

Despite numerous recommendations CCN services have been slow to develop with only 50% of NHS Trusts in 1997 in England and Wales providing a CCN service. Provision of this service for sick and disabled children is therefore patchy. Adult patients at home have received the

benefits of a district nursing service for many years. Children have a right to a comparable nursing service thus it is important and urgent that the expansion of CCN services continues.

It has been suggested that CCNs are in a unique position to be of real assistance to all members of the family affected by childhood LTI (NAHA, 1988; Proctor et al, 1999). The CCN can play a crucial part in ensuring compliance with treatments and adapting the child's care to individual family circumstances (Proctor et al, 1999). One of the main elements of children's home care is flexibility (Dominica, 1990a). For example, the CCN can move in and out of the family system as necessary (Whyte, 1992), is a co-ordinator (NAHA, 1988), a supporter (While, 1992), facilitator (Norman & Bennett, 1986) and link person (Gow & Ridgeway, 1993). The CCN can provide information (While, 1992), offer practical nursing and respite care (Dryden, 1989a, 1989b; While, 1992); teach health care skills to the child, parents (Kendrick, 1993, Proctor et al, 1999) and professionals from other organisations (de Rome and Sykes, 1995) and offer terminal care and bereavement support (RCN, 1994). An effective CCN recognises the caring burden experienced by the family and their need for support and encouragement to manage their situation which exceeds considerably normal parenting responsibilities (While et al, 1996a; Proctor et al, 1999). With appropriate help most children can be cared for at home (Goldman et al, 1990). This form of care is acceptable to families and for most parents it is their preferred choice (While 1991) and allows siblings, grandparents and other important family members to contribute to the caring role (Curnick, 1990). The CCN can be instrumental in anticipating the needs of family members in a proactive rather than reactive approach to care which emphasises the need for preventative measures (Proctor et al, 1999).

The gap in the literature lies with the paucity of rigorous and robust nursing research to evaluate the roles of specialist children's nurses. It is the aim of this study to reduce this deficiency by examining, with quasi-experimental methodology, the effect of nurse-led interventions on family need. Proctor et al's (1999) recent study was not designed to test the effectiveness of CCN

services and thus their developmental model for CCN practice is proposed from evidence derived from patterns of CCN work and family need. Fradd (1992) has described the children's nurse as a specialist practitioner, and the newly formed Diana Nursing Teams will provide a specialist home care service for children with LTIs and their families. Community nursing skills and qualifications can also be defined as specialist (Proctor et al, 1999), where the emphasis is on generalist skills delivered from a non-categorical rather than disease specific service approach underpinned by family-centred care. Controlled evaluative studies to test the effectiveness of interventions on child and family outcomes provided by CCN services are now required to build upon the pilot work which has explored the needs and experiences of this group of children and their families.

Chapter 3 Methodology

3.1 Study aims and objectives

The research was designed to provide evidence of the needs of families caring for children with a LTI. The literature revealed a paucity of robust research evidence pertaining to family need and childhood LTI, therefore, an exploratory methodology was used which combined quasi-experimental and qualitative elements. Six domains of need identified from the literature were: informational, practical, social, emotional, financial and educational which formed the focus of the study. The quasi-experimental component allowed for the piloting and evaluation of nurse led interventions in relation to family expressed need under the auspices of a newly established CCN service funded and managed by a community NHS Trust.

3.1.1 Research questions

Two questions were posed to meet the study aims and objectives:

1. Do families caring for children with a LTI have common needs and characteristics which outweigh specific problems generated by the illnesses themselves?

2. Can nurse-led interventions make a difference to the level of expressed continuing care needs of families living with childhood LTI?

3.2 Design of the study

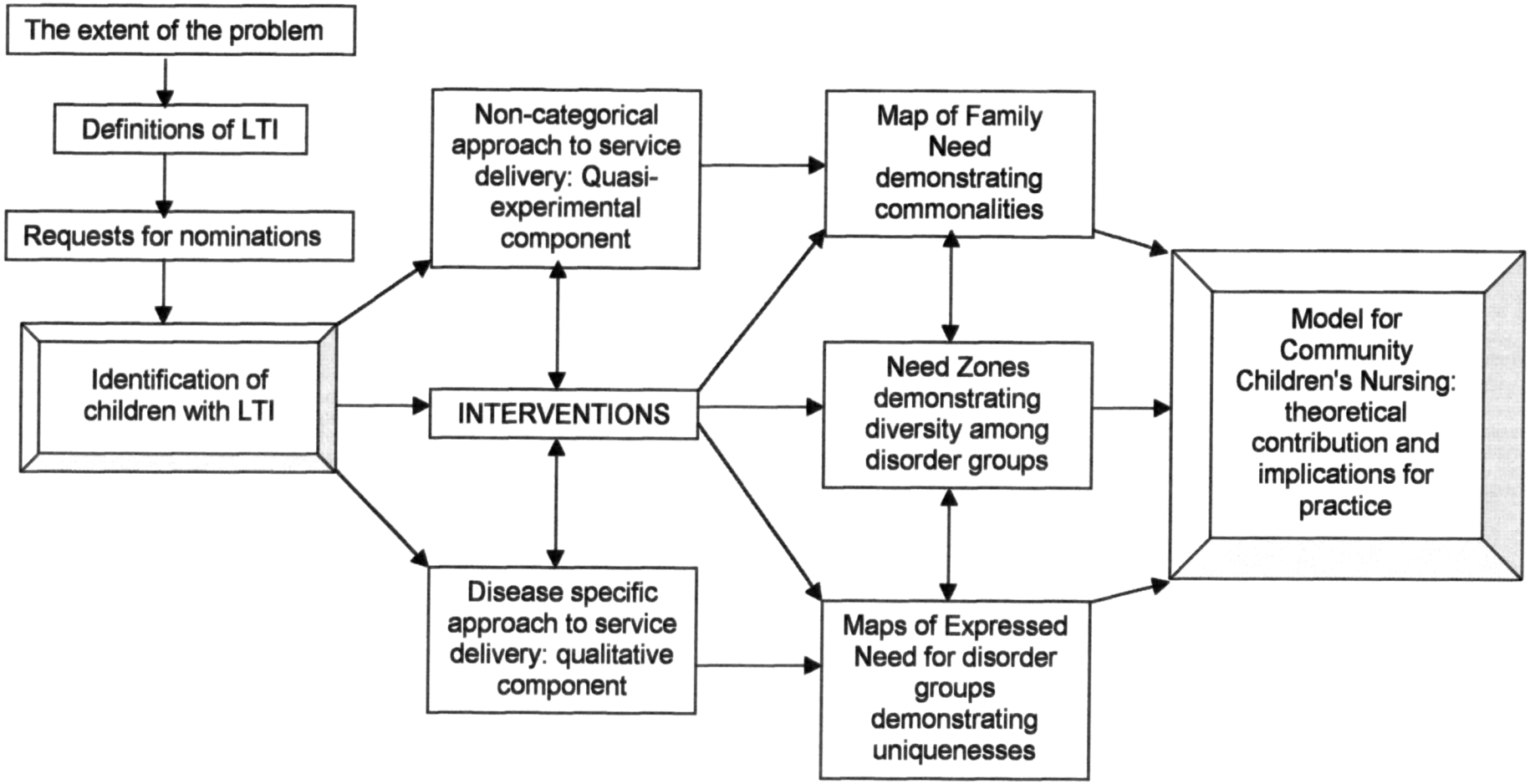
The gap between scientific evidence obtained through experimental methods and clinical practice can be bridged by the use of qualitative methods (Green & Britten, 1998). The value of qualitative methods lies in their ability to investigate, in a systematic way, research questions which do not easily lend themselves to experimental methods such as those which explore family needs, attitudes, beliefs and preferences. In the evidence-based practice

debate, 'good evidence' goes further than those scientific results achieved through the use of the randomised controlled trial (Green & Britten, 1998). Therefore, it was perceived as important to combine quantitative and qualitative methodologies in this exploratory study so that "their respective strengths might be reaped" (Bryman, 1988 p. 127). (Figure 1).

3.2.1 Overview of the study design

Analysis of local childhood mortality data was undertaken and formed the basis of an operational definition which was used to identify children with a LTI living within the boundaries of an English health district. Due to the greater than expected number of children identified with a LTI it was not possible to interview all families. Therefore a random sample of 30 families, stratified by illness groupings, was selected to participate in the study as an intervention group. A reserve list was drawn up in the same manner in case some families declined to take part. Those families who were neither selected for participation nor in reserve were placed on a 'wait list'. At the end of the recruitment process those families who had not been approached for the intervention group and those on the wait list became the control group for invitation to participate in a single interview. Families agreeing to participate in the intervention group were interviewed on three occasions over a one year period to determine their level of need and to highlight areas requiring interventions. Qualitative data were obtained from tape-recordings of these interviews which were transcribed verbatim. Nurse-led interventions were initiated as a consequence of family needs identified during the interviews. The effects of interventions were monitored with the evaluation of family need during subsequent interviews. Three families participated in a pilot study to test the acceptability of the interview design and to allow the researcher to become familiar with the interview format.

Figure 1 Quantitative and qualitative components of the study



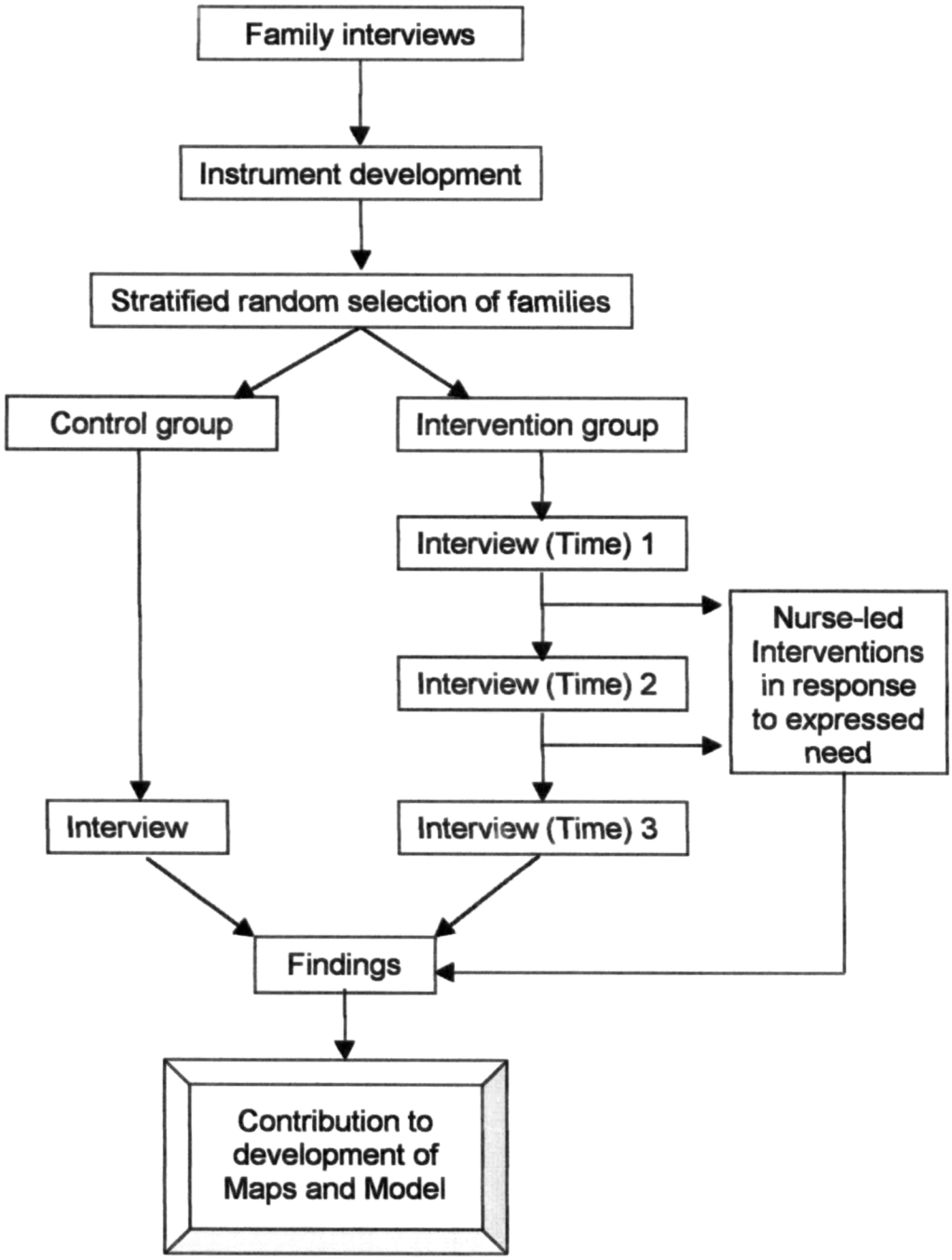
3.2.2 Development of an operational definition

An inventory of life-limiting and LTIs was developed (Appendix 1) based on three sources: 1) the literature; 2) the following definition: "An illness where medical intervention may prove successful but where there is substantial chance of mortality in childhood or early adulthood" (ACT, 1993); and 3) an analysis of the ICD 9 codes (WHO, 1975) of childhood deaths occurring between 1988 and 1992 of residents aged below 19 years in the health district where the study was performed (Maynard et al, 1996). The broad definition proffered by ACT (1993) encompassed a range of illnesses such as cancer; severe organ failure, for example, blood disorders and heart, liver and kidney disease; metabolic disorders such as cystic fibrosis and mucopolysaccharidosis; progressive degenerative disorders, for example, spinal muscular atrophy and muscular dystrophy; profound disability, resulting from birth asphyxia or cerebral palsy; and chronic conditions conferring oxygen dependency and / or tracheostomy.

3.2.3 Quasi-experimental component

A quasi-experimental design was chosen as the best method for achieving the aim of the study concerned with examining the effects of nurse-led interventions on family need (Figure 2). Quasi-experimental studies were developed to provide an alternative method of examining causality in situations (Cook & Campbell, 1979) where, for ethical and / or practical reasons, at least one of the elements of a true experiment (random sampling, control groups, and the manipulation of the intervention) was missing (Burns & Grove, 1993). However, the degree of control over extraneous variables is not high thus it is not possible to state with certainty that any new intervention tested within such a design is actually responsible for the effects measured. Therefore, quasi-experimental designs can at best establish links between causality and effect. One of the strengths of the quasi-experimental design lies in the fact that findings may be more generalisable than those of true experiments because they take place in a natural setting and can therefore, closely resemble the context in which families live (Parahoo, 1997).

Figure 2 Process of quasi-experimental component



The quasi-experiment of choice was an untreated control group design with pre-test and post-test (Burns & Grove, 1993) as this design is generally interpretable with threats to validity primarily relating to the non-equivalent control / comparison group (Cook & Campbell, 1979). However, a number of factors prevented a pre-test being performed with the control group. Firstly, there were ethical implications of identifying needs in control group families

and then being unable to respond to areas of unmet need. Secondly, time constraints and obligations to the employing community NHS Trust prevented the use of a more controlled evaluative study. The researcher had sole responsibility for designing the research, collecting and analysing data, initiating nurse-led interventions with families and intervening within the organisation to raise the profile of the CCN service. This highlights difficulties faced by practitioners undertaking research in their own field of practice (Whyte et al, 1998). Cook and Campbell (1979) have argued that post-test data should be collected by someone other than those responsible for providing the intervention(s) in order to reduce the risk of bias.

The researcher was aware of potential threats to the internal validity of the study, for example, developing different depths of relationships with families of differing personalities and that very 'needy' families may have required extensive interventions to the detriment of others. In addition, the researcher was aware that demanding families may impinge on her time and that 'less vocal' families may not fare so well. An awareness of such issues enabled the researcher to give every family an equal chance of utilising the service offered and to minimise their effects as much as possible.

3.2.4 Qualitative component

The qualitative researcher faces numerous difficulties. For example, the labour-intensiveness of data collection, the time-consuming nature of processing and coding data with the frequent possibility of data overload and researcher bias, the questionable usefulness and generalisability of findings from small sample sizes, not least the quality and credibility of conclusions, have all been recognised (Miles & Huberman, 1994; Morse & Field, 1996). Miles (1979) described the most problematic area of qualitative research to be the lack of practical guidelines and well formulated methods of analysis. As with experimental research those involved in qualitative studies should be explicit and systematic in describing their methods of analysis so that they can be replicated. The analysis process was facilitated by the use of the qualitative data analysis software package QSR NUD*IST version 4.0.

Storage, sorting and retrieval of data were computer assisted, however, the development of themes was undertaken by the researcher.

3.3 The sample

3.3.1 Process for nomination of children

Identifying children with LTI proved difficult as the local 'special needs' register did not record data concerning children less than five years of age or those with illnesses such as cancer and heart disease (Maynard et al, 1996). Thus, it was necessary to survey primary and secondary health care professionals who were given the operational definition of LTI (3.2.2) and requested to nominate families caring for a child with a LTI from their caseloads. A wide range of professionals were surveyed to maximise the potential nominations and to avoid the exclusion of any child who might meet the study criteria. Every general practitioner (GP), health visitor (HV), school nurse (SN) and specialist children's nurses employed in the study area was surveyed as well as the paediatric wards in the university teaching hospital which served as both a tertiary referral centre for children with cancer and neurological trauma and a District General Hospital for the local community.

Nominations were checked to remove duplication, and then reviewed by a panel consisting of a general practitioner, a consultant community paediatrician and the researcher, using the set of entry criteria defining eligible diagnoses (Appendix 1). Each child was considered on an individual basis and a judgement made to determine the presence or absence of a LTI. The panel used their combined clinical expertise and where necessary sought information from the child's community and hospital medical records. On this basis children aged less than 19 years resident in the health district with a LTI were identified and placed in the sampling frame for randomisation to the intervention group. The nominating health professionals of those children not meeting the entry criteria were informed of the panel's decision by letter and offered the services of the newly appointed CCN (1.2).

3.3.2 Sample selection

From the sampling frame a stratified random sample of families was drawn to comprise the intervention group. Families were contacted in the first instance by mail via their nominating professional (HV, SN, specialist nurse), inviting them to take part in the study. Families willing to participate responded directly to the researcher. The letter of introduction gave written assurance that families were under no obligation to participate and that the services which they were currently receiving would not be affected should they decline to participate. The process of recruitment of families on the 'wait list' mirrored that of the intervention group and occurred at the time the intervention group families were undertaking their third and final interview.

Selection bias was controlled to a limited extent by the randomisation process which prevented health professionals already in contact with families from choosing those whom they felt were more or less deserving of the intervention service (Beresford et al, 1996). The researcher did not have prior knowledge of the sample as she was new to the geographical area. Stratifying the sampling frame by 16 illnesses ensured that all diagnoses were represented (Burns & Grove, 1993). The CF grouping was the largest diagnostic group represented and was divided into two by age (<9 years & >9 years) again to control for bias relating to the age of the child. The other illness groupings were relatively small and thus it would have been inappropriate to control for factors such as age. It was decided for ethical reasons not to undertake the randomisation after families had agreed to participate thereby avoiding raising family hopes and expectations. Thus all families in the sampling frame had an equitable chance of participating and having access to the service.

3.3.3 Sample attrition

A degree of sample attrition was expected. For example, due to the LT nature of their illnesses several children died either before their families were approached or during the data collection period itself. Other families had

moved away from the area and some simply did not want to participate. However, one factor was not anticipated. Some health professionals (HVs, SNs and one specialist nurse) who had identified families in the nomination survey refused to approach a family with the introductory information inviting them to participate. Those health professionals who gave reasons for their decision suggested that they perceived families to be inundated with professional contacts and that it would be inappropriate, in their opinion, to inflict further pressure upon them by inviting them to participate in a research and intervention study. Others perceived themselves as saving the researcher time by approaching families whom they knew would not participate. With either reason, this selection bias was completely out of the control of the researcher and may have meant that some families in need were denied help by well meaning professionals.

3.4 Ethical issues

Local Research Ethics Committee approval was sought and secured prior to contact with families. Due to the sensitive nature of the research an informal and empathetic approach to the interviews was adopted by the researcher at all times. Previous clinical practice in the paediatric intensive care speciality gave the researcher an understanding of the needs and problems faced by families caring for seriously ill and dying children and of relating to parents about potentially distressing issues. Concerns were voiced by nominating health professionals that some families may not have come to terms with their child's disorder or were unaware of the LT nature of the illness. Consequently, letters and written information for parents used the term 'long-standing, serious, physical illness'. During the interviews reference to the LT nature of the illness was not discussed unless raised by the families themselves. A prompt by the researcher asking about their worries or concerns for the future offered parents the opportunity to discuss the potentiality of their child's death if they wished.

3.5 Data collection: tools and measures

3.5.1 Questionnaire

In the absence of standardised measures to assess the needs of families caring for children with LTIs a tool needed to be developed. Following an extensive review of the literature four distinct elements were developed. Three elements were structured: 1) an assessment of family need with the modified perceived needs scale (3.5.2 & Appendix 2); 2) an assessment of the coping strategies used by families with the Coping Health Inventory for Parents (CHIP) (McCubbin et al, 1983; 1996) (3.5.3); and 3) an assessment of the child's functional ability regarding activities of daily living (such as eating, dressing, mobilising etc) and caring interventions performed by parents (e.g. administration of medicines and suctioning) (Appendix 3). The fourth component was semi-structured and focused on the family's experiences of caring for their child. An aide-memoire was developed to assist the researcher (Appendix 4). The purpose of the semi-structured format was to encourage the family to relate 'their story' and to enable them to raise issues which concerned them, as well as being able to respond to 'prompts' (areas identified from the literature as being of likely importance) from the researcher.

The recruitment interview for intervention and control groups comprised all four components. Subsequent interviews at six and 12 months consisted of the modified perceived needs scale, assessment of the child's functional ability and a semi structured element which allowed parents to raise any contemporary issues which concerned them or problems which they had experienced since the previous interview.

A functional ability score was derived for each index child at each interview by re-coding each of the 10 activities of daily living items to create either 'normal' or 'abnormal' ratings. For six of the 10 items ability was also a function of the child's age and physical development thus the seminal work of Sheridan (1973) was used as a guideline to control for age related bias.

Where appropriate an item was re-coded for "normal" if the original answer given by the respondent was as a consequence of the child's age and normal physical development. Thus, a score between 0 and 10 (where 0 corresponded to full functional ability and 10 corresponded to no independent functional ability) was computed for each child. For those families with two affected children the scores for the youngest child were disregarded to facilitate comparison between families.

A caring intervention score was derived for each child at each interview by counting the positive responses for the 16 variables pertaining to the practical caring interventions undertaken by parents. Thus, an intervention score between 0 and 16 was obtained for each child where 0 = no caring interventions performed by parents and 16 = every listed intervention performed by parents. Caring intervention scores of second affected children were also discarded when necessary.

3.5.2 Perceived Needs Scale

The family's level of need was measured using a modification of the Perceived Needs Scale (Quine & Pahl 1989; Appendix 2). The original instrument contained 22 items describing forms of help which parents of children with learning disabilities sometimes needed and was modified to reflect the different needs of families caring for a child with a LTI. Ten of the original 22 items were retained and a further 11 items were included describing forms of help identified from the literature and which reflected the principles of the ACT Charter (1993). These 21 items investigated a range of needs which were categorised for this study into six domains: Informational; Practical; Social; Emotional; Educational and Financial.

Questions were phrased to encompass the needs of the entire family but with the exception of the recruitment interview, interviews were conducted with the principal carer. For each item respondents were asked to indicate the most appropriate answer for their family from a list of five responses: (1) getting enough help; (2) already getting some help but would like more; (3)

not getting any help but need it; (4) not getting any help but don't want it; (5) not a problem / not applicable. At data analysis the responses were grouped into two categories: the first category comprised responses (1), (4) and (5) and described 'no further help required or desired by the family at this time'; the second category comprised responses (2) and (3) and described 'family expressed need for additional help at this time' (Sloper & Turner, 1992).

A global need score was obtained for each family at each interview by summing the number of items in the modified perceived need scale where families expressed a need for additional help. Therefore, a score between 0 – 21 was possible for each family at each interview. Need domain scores for each family were derived in a similar way by summing the items where families expressed a need for additional help in each of the six need domains. The range of possible scores for each domain were: informational 0-3; practical 0-5; social 0-4; emotional 0-4; educational 0-2; financial 0-3.

3.5.3 Coping Health Inventory for Parents (CHIP)

McCubbin et al (1983; 1996) developed a 45 item tool to assess the extent to which parents found different strategies helpful in coping with their child's illness. Factor analysis of the responses of 95 mothers and 90 fathers of children with CF resulted in three positive coping patterns. Factor 1 concerned family life and the maintenance of relationships (family integration) and focused on behaviours concerned with family's beliefs about life and the illness and which encouraged family unity. Factor 2 comprised items which centred on parents' efforts to maintain a feeling of contentment through their social relationships (social support), and factor 3 focused on the relationships between parents and health professionals and other parents also caring for a sick child (medical communication). The reported Cronbach's alphas for the three factors were 0.79, 0.79, 0.71 respectively. CHIP scores were derived for mothers for each of the three patterns of coping.

3.6 Data collection: process

A series of three tape-recorded interviews at recruitment (baseline interview Time 1), at six (interview Time 2) and at 12 months (interview Time 3) were conducted with families in the intervention group between April 1994 and June 1995. Controls undertook the recruitment interview (Time 1) at the end of the study (i.e. at 12 months). All interviews were conducted in the families' own homes at a mutually convenient time. Prior to commencing the recruitment interview parents were assured of the confidentiality of information and gave their written consent for participation and for interviews to be tape-recorded. At each interview parents were informed of their right to withdraw from the study which would not affect the services or interventions which they were receiving. Where possible both parents participated in the recruitment (Time 1) interview with some interviews taking place during the evening to allow both parents to be present.

Interviews are perceived by some as the most useful method for collecting rich and quality data despite the fact that they are often more time consuming and costly (Burns & Grove, 1993). The interview method allowed for further explanation of the purpose of the study and the opportunity to clarify any questions which were not clear. In addition, it was envisaged that interviewing families three times in a one year period would encourage a rapport to be established between the researcher and family and thus interviews were more likely to elicit a deeper depth of response. The quality of information elicited from an interview depended upon the researcher's interpersonal skills and ability to establish a rapport and thus gain the trust of the respondent(s) (Morse & Field, 1996). The potential for bias is acknowledged but was minimised with all the interviews being conducted by the researcher. Thus, any bias may have been consistent and therefore gone unnoticed (Bell, 1987). A potential negative consequence of the establishment of such a relationship may have created problems with data collection at the final interview (Time 3), with families expressing less need in order to 'please' the researcher (Beresford et al, 1996).

3.7 Interventions

A range of interventions were possible under the auspices of the newly formed CCN service in response to areas of unmet need highlighted during the recruitment (Time 1) interview. It was likely that three types of intervention would be performed: 1) on an individual family basis; 2) specific projects for groups of families who expressed needs in common; and 3) those which would contribute to the strategic planning and policy making concerning the CCN service in the study area. The researcher had limited funding available for the development of such initiatives.

3.8 Strategies of analysis of data

3.8.1 Analysis of quantitative data

Table 1 Strategy of analysis of quantitative data

Test	Comparison
Fisher's Exact	• Professional groups in nomination process
Mann-Whitney U	• Global need scores of intervention group between Time 1 and Time 3 • Global need scores between intervention group and control group at Time 1
Wilcoxon Matched pairs Signed Ranks	• Global need scores of intervention group families between interviews: - Time 1 and Time 2 - Time 1 and Time 3 - Time 2 and Time 3 • Need domain scores of intervention group families between interviews: - Time 1 and Time 2 - Time 1 and Time 3 - Time 2 and Time 3
Kruskal-Wallis 1 way ANOVA	• Functional ability scores between four disorder groups • Caring intervention scores between four disorder groups • Global need scores between four disorder groups

Statistical analysis using non-parametric tests (Siegel, 1956) was conducted

using SPSS for Windows Version 6.0. All tests are 2 tailed, with an alpha value of 0.05 being accepted. (Yate's continuity correction was used where appropriate). The small sample size hindered further examination of relationships between global need, functional ability and caring intervention scores and differences among and between disorder groups.

3.8.2 Analysis of qualitative data

3.8.2.1 Initial coding process

A provisional list of codes was drawn up prior to commencing preliminary coding of the interview transcripts. The aim of this process was to label data efficiently and assist in the retrieval and analysis process. The initial coding scheme constituted the six major need domains with sub-divisions of 21 codes derived from the individual items in the modified perceived needs scale. In addition, activities of daily living were listed in order to facilitate the coding of portions of data concerning the child's functional status. Further, a list of codes reflecting likely caring interventions was produced to examine factors which might influence a family's need for additional help. Thus, this scheme was generated from key variables derived from the literature and the study aims, and was a helpful and useful method of initiating the coding process (Miles & Huberman, 1994). This preliminary coding scheme was short enough to fit on one sheet and be retained in the researcher's short-term memory. In addition, it facilitated the process of checking for reliability in the coding process.

To examine the internal consistency of the preliminary coding process check-coding of the same transcripts was performed by the researcher after five interview transcripts had been coded using the inter-coder reliability formula proposed by Miles & Huberman (1994 p. 64). Code-recode consistencies of 82% were achieved in the first instance, rising to 93% when reliability was checked again after 20 interview transcripts had been coded. The researcher held a series of three meetings with a psychologist and GP to clarify definitions and descriptions of codes and themes. These professionals were

members of the study's steering committee and each coded the same five interview transcripts using the initial coding scheme. Inter-coder reliability scores of 69% and 71% were achieved when comparing the researchers' coding with the GP and psychologists' coding respectively using the reliability formula. Codes and themes were discussed which assisted the researcher in clarifying definitions and enhanced rigour and trustworthiness of the coding schedule (Miles & Huberman, 1994; Morse & Field, 1996).

The coding scheme was constantly amended as new themes emerged, a process facilitated by the use of QSR NUD*IST version 4. Further analysis of the text coded within the six need domains revealed mutual exclusivity to one of three additional categories: 1) description of the family's present situation; 2) description of the family's past experiences and 3) an expression of current need for additional help. This third category defined as, 'the expressed need data', was considered a manageable amount of data concerning the continuing care needs of families from which in depth analysis could be undertaken.

3.8.2.2 Analysis of 'expressed need' data

The process of analysis of expressed need (Figure 3) was repeated for each interview transcript obtained from the intervention group i.e. at Time 1, Time 2 and Time 3 and with Time 1 data obtained from control group families. It followed the methodological process outlined by Miles and Huberman (1994) in their exploration and description of cross-case displays. This method is useful in enhancing generalisability as well as deepening understanding and explanation of a situation. The use of multiple cases allowed for the examination of similarities and differences across cases and assisted the researcher in identifying negative cases which could strengthen a theory. It also highlighted specific factors affecting a finding as well as assisting in the development of more general categories depicting how factors may be related. However, a degree of caution is advocated to preserve the uniqueness of individual cases as the need for general understanding of generic processes is sought (Miles & Huberman, 1994).

The verbatim expressed needs from the interview transcripts were displayed in a large meta-matrix. This formed a master chart of data which included all relevant data in their simplest form i.e. as spoken by the respondent. The first step in analysis involved summarising these verbatim quotations of expressed need into short manageable sentences before partitioning them by four disorder groups (DG) which were generated by grouping families whose children's illnesses were similar, either diagnostically and / or in their need for particular services. The four disorder groups were:

DG1 Disorders requiring intensive medical support / resources;

DG2 Progressive degenerative disorders;

DG3 Disorders resulting in organ failure;

DG4 Disorders resulting in profound disability.

The summaries of verbatim quotations were thus ordered to facilitate the clustering of data which resembled each other or fell together. In addition, data were further clustered into the six need domains pre-determined from the literature and the classification used in the quantitative analysis. This facilitated comparison between quantitative and qualitative findings. At this point the expressed needs were further refined and summarised by disorder group and need domain.

Individual meta-matrices for the expressed needs from the three interviews with the intervention group were developed. Thus it was possible to make a comparison across time. These serial data highlighted themes which reflected a constancy of need for certain disorder groups and in certain need domains.

Themes became apparent and the next major step involved displaying these themes in meta-matrices by disorder group and need domain. These theme grounded phrases were a middle range of abstraction (Miles & Huberman, 1994). Refinement of themes continued and commonalities and diversity among groups were identified. At this point, expressed needs became more abstract. A theme could be generated by a single instance in the data and was not dependent on the number of cases in which it appeared (Glaser & Strauss, 1967). Thus, the development of themes was not intended to portray

a frequency distribution among families as the analysis was of expressed need among disorder groups and not of the individual needs of the families.

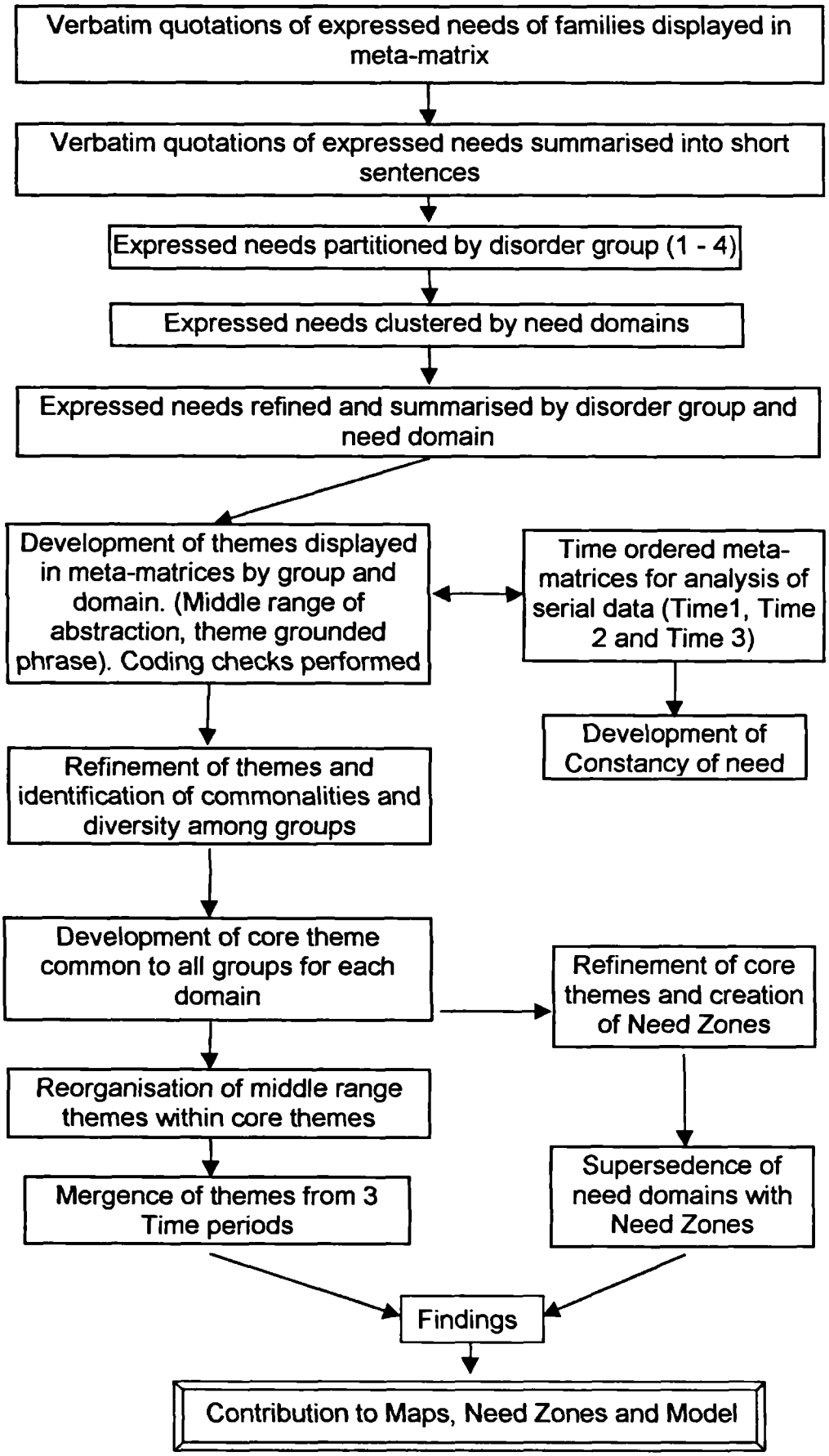
A core theme common to all groups for each of the six domains was identified. As these were refined Need Zones evolved which reflected the themes more closely than the original need domains. Thus Need Zones superseded need domains. Middle range themes were re-organised within these central themes and the meta-matrices from all three interviews were merged. Therefore, the 'snap shot in time' regarding family expressed need became a one year period.

Analysis of the composition of disorder groups within the control group revealed an imbalance in the numbers of families comprising the different groups (DG1 n=1; DG2 n=7; DG3 n=4; DG4 n=1). Thus, it was decided, as themes were not intended to portray a frequency distribution but to represent the disorder group as a whole, to incorporate control group data into the Time 1 data of the intervention group and not to undertake a comparison between the expressed needs of intervention and control groups.

3.8.2.3 Presentation of findings

The evaluation of expressed need consisted of micro, mezzo and macro levels of analysis. The micro level within the six need domains and of factors which may affect the needs of families most closely reflected the summaries derived from the verbatim quotations and enabled the generation of higher range of abstraction themes. The analysis of expressed need is presented by disorder group and need domain in alphabetical order. No individual domain was perceived as more or less important during the analysis process. Similarly, the findings from each disorder group are presented in number order. The numerical classification of disorder groups was arbitrary and the expressed needs of families comprising the disorder groups were considered commensurate.

Figure 3 Process of qualitative analysis of expressed need data



It is the intention of the researcher to report the findings from each group consistently and as objectively as possible. Themes generated from the expressed needs in the disorder groups which were evident in all three interviews are reported as a Constancy of need.

Analysis of factors likely to affect need on a micro level are also presented. Functional ability of children is reported by disorder group and each activity of daily living while, to avoid repetition, analysis of caring interventions performed by parents is reported by theme only.

The identification of core themes common to all disorder groups enabled the generation of Need Zones and contributed to the development of Maps of Expressed Need for each of the four disorder groups. Within this mezzo level of analysis commonality and diversity of factors likely to influence need among the disorder groups for functional ability and caring interventions performed by parents were also identified. This facilitated exploration of the relationship between expressed need and factors which might affect need in each of the disorder groups.

Findings on a macro level of analysis are presented in the Map of Family Need. The identification of commonalities among the disorder groups found in the higher range of abstraction themes of expressed need were reproduced from the tables in Appendices 5-22 and incidences checked to remove duplication.

Appendices 5-22 consist of a series of 18 tables which comprise: the researcher's summary of every incidence of coded text pertaining to expressed need; emergent middle and higher range of abstraction themes within each of the six original need domains and for each of the interviews (Time 1, Time 2 and Time 3). Thus these tables should be used in conjunction with the main text in the exploration of commonality and diversity among disorder groups. A further series of tables (Appendices 23-42) are produced for use alongside the micro level of analysis of factors likely to affect need. These tables record by theme the summaries of each incidence

of coded text concerning child functional ability ordered by activity of daily living (Appendices 23-32) and caring interventions performed by parents (Appendices 33-42).

An essential factor in qualitative data analysis is to report findings in such a way that the reader can be left in no doubt that the emergent themes have been generated from the data and do not appear as if by magic (Miles & Huberman, 1994). Accordingly, in Chapter 6 verbatim quotations are used to illustrate theme generation. In addition, they also illuminate the presence of Constancy of need within the domains and disorder groups. Names of children, professionals and disorders have not been reproduced to protect the identity of participating families. Minor changes have been made to the verbatim quotations to improve clarity. Explanations of situations provided by the researcher are shown in parentheses.

3.9 Summary

The ACT (1993) definition of LTI was used as the basis of an operational definition: "An illness where medical intervention may prove successful but where there is substantial chance of mortality in childhood or early adulthood". Health professionals were surveyed to identify potential participants. Families meeting the study criteria (child had a LTI; aged < 18 years; lived in the study area) were stratified by illness group and a random sample selected. A combination of quantitative and qualitative methods were used to explore the needs of families and evaluate the effectiveness of nurse-led interventions. In the absence of standardised measures to assess the needs of this group of children and their families a questionnaire was developed which comprised structured and semi-structured components. A series of three tape-recorded interviews were undertaken with intervention group families over a one year period during which time nurse-led interventions were initiated in response to expressed needs. Comparisons were made with a control group of families who did not receive interventions and between four disorder groups which comprised the intervention group. Strategies of analysis of data included the use of non-parametric statistical

tests and the generation of themes from interview transcripts. Findings from the quantitative and qualitative components of the study were merged in the development of Maps of Expressed Need for each disorder group; Models for the six Need Zones; The Map of Family Need and a dynamic model for Community Children's Nursing.

Chapter 4 The Children And Their Families And Their Context Of Care

4.1 Nomination of children

The frequency of children nominated by professional groups, the number of children confirmed by the specialist panel to have a LTI and the proportion of nominated children meeting the study criteria are shown in Table 2. Other professionals surveyed e.g. specialist children's nurses (asthma, oncology outreach and community children's nurse) and a social worker who had not been surveyed directly nominated 23 children between them, all of whom had some form of LTI.

Table 2 Source and frequency of nominations of children

Professional group	Response rate (%)	Children nominated	Children confirmed by panel to have LTI	Success rate of nomination % (95% CI)
General practitioner (n=191)	67	39	24	62 (44.1-76.6)
School nurse (n=20)	90	92	42	46 (35.2-56.4)
Health visitor (n=45)	90	98	34	35 (25.4-45.0)
Other (n=7)	-	23	23	100 (35.4-100)

Almost two thirds of the children (62%) nominated by GPs had a LTI. General practitioners were significantly more successful than nurses in their nomination of children considered by the specialist panel to have a LTI ($p = 0.02$). Nurses were less successful in their nominations, with just under one half (42%) of the children nominated by SNs and only one third (35%) of those nominated by HVs meeting the study criteria. Although GPs were significantly more successful in nominating children when compared with HVs alone ($p = <0.01$) there was no difference between GPs and SNs alone, nor between SNs and HVs.

The total number of individual children nominated from all sources was 183

of whom 47% (86) were judged by the specialist panel to have a LTI. Of these, 35 (40%) were nominated by more than one source and the frequency and distribution of the LTIs are outlined in Table 3. A variety of LTIs were identified and the largest groups represented were CF (16.3%) and neuro-muscular degenerative disorders (e.g. Duchenne muscular dystrophy and spinal muscular atrophy) (13.9%). Other main illness groups were: profound disability (10.5%); renal disease (9.3%) and cancer (8.1%). A purposive sample of three families participated in the pilot study thus the sampling frame (stratified by 16 illness groups) for the purposes of randomisation consisted of 76 families, seven of whom cared for two affected children.

Table 3 Frequency and distribution of LTI (January 1994) n=86

Life-threatening illness	Children
Cystic fibrosis (< 9 years)	8*
Cystic fibrosis (> 9 years)	6
Neuro muscular degenerative disorders	12
Profound (learning and physical) disability	9*
Renal disease and transplantation	8
Cancer and leukaemia	7
Severe asthma	6
Metabolic disorders	5
Severe food allergy (requiring access to epinephrine)	4
Downs syndrome and inoperable cardiac disease	4
Cyanotic cardiac disease	4
Liver disease and transplantation	4
Inherited blood disorders	3
Tracheostomy	3
Apnoea	1
Oxygen dependency (from premature birth)	1
Primary immune deficiency	1*

*Participation of one family in pilot study

4.2 The children and their families

4.2.1 Sample attrition

Between the time of nomination of families by health professionals and the recruitment of the intervention group (six months) the families of nine children had reason to be excluded from the study: two children had died; three families had moved out of the area; one child had recovered following

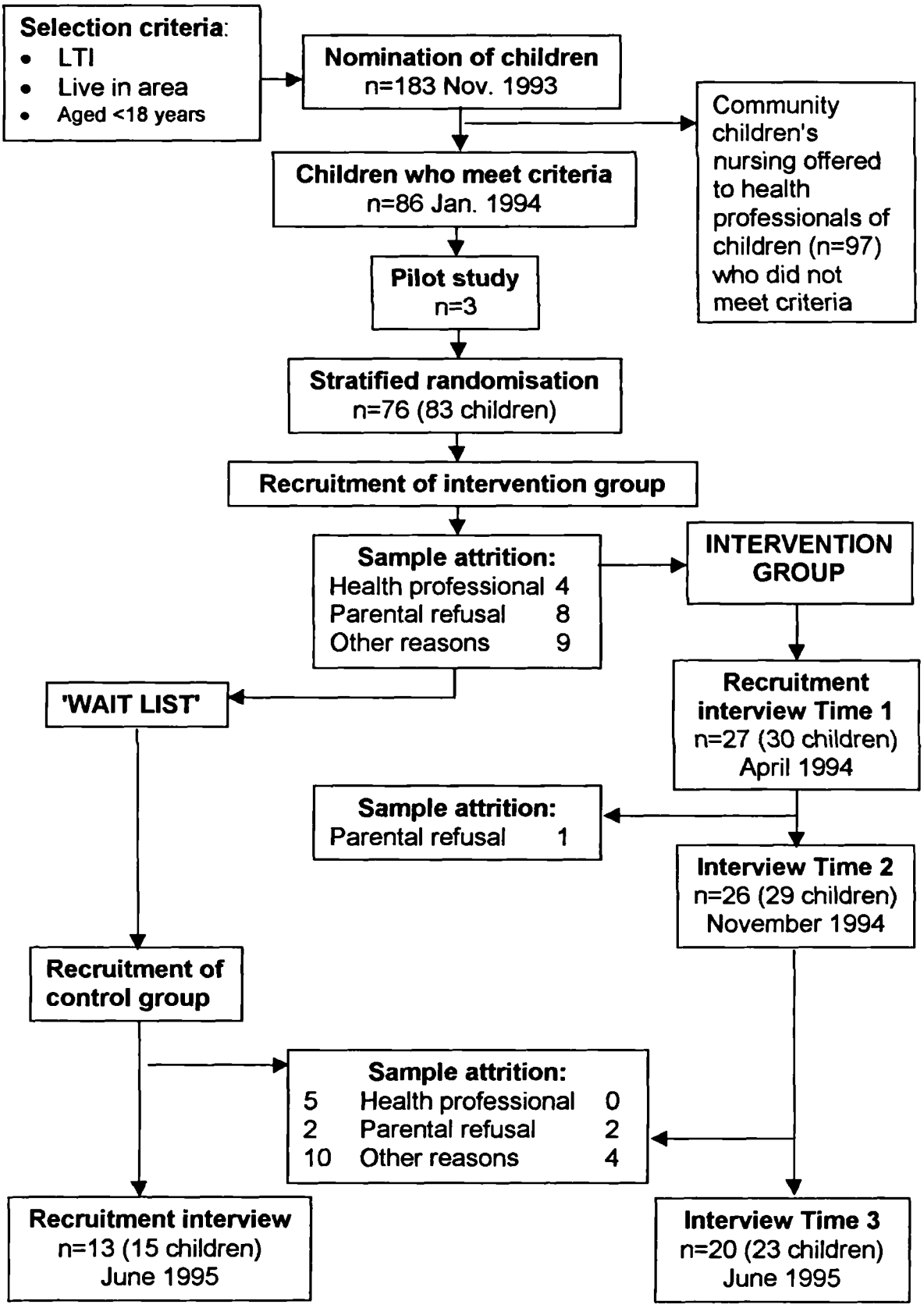
surgery; and a parent of one child joined the study's steering committee. Two children in the same family had been incorrectly allocated to the sampling frame, because they attended a special needs school in the area but lived outside the study's geographical boundaries (Figure 4).

During the two periods of recruitment (for intervention and control groups) eight families refused to participate in the intervention group and two families declined to be interviewed as part of the control group. Three families gave reasons for refusal: two felt that their child was 'too well' and another felt overwhelmed by statutory service involvement. Nine nurses declined to approach the families whom they had identified during the nomination survey (Figure 4).

Reasons for sample attrition prior to the recruitment of control group families other than direct refusal were: one child died; two families moved away; two children had successful cardiac surgery; two children were receiving CCN support (1.2). Three children had been wrongly allocated to the sampling frame: one lived outside the locality despite attending a school in the study area; one child had a non-progressive chronic illness and one was 19 years old (Figure 4).

Reasons for sample attrition of intervention group families after the recruitment interview were: one child died; three families refused (all felt their children to be too well); and one family moved away. Two families were late entrants to the study and therefore a year had not elapsed between the recruitment interview and completion of data collection (Figure 4).

Figure 4 Selection process and timing of quasi-experimental component



4.2.2 Family interviews

Twenty seven families were recruited into the intervention group three of whom had two affected children and were interviewed during April 1994 (Time 1). Second interviews took place in November 1994 (Time 2) with 26 families (29 children). Final interviews for the intervention group took place in June 1995 (Time 3) with 20 families (23 children). Recruitment interviews for the 13 families (15 children) participating as the control group also took place during June 1995 (Figure 4).

4.2.3 Characteristics of children and families at recruitment

Table 4 Distribution of children by age range and gender at recruitment

Age band & gender	Intervention group n=30 (%)	Control group n=15 (%)
< 5 years	10 (33.3)	4 (26.7)
5 – 10 years	16 (53.3)	8 (53.3)
11 –18 years	4 (13.3)	3 (20.0)
Male	18 (60.0)	5 (33.3)
Female	12 (40.0)	10 (66.7)

Children in the two groups were evenly distributed across the age range despite the sample not being stratified or randomised for age (except for the two groups of children with CF). Just over half (53.3%) of each group fell within the 5-10 year age band. Randomisation by gender was not performed and although there was some disparity between intervention and control groups, boys (n=23) and girls (n=22) were equally represented when considering the whole sample (n=45) (Table 4).

Nine categories of illnesses were represented (Table 5). The largest illness group was CF (20%). Other principal illness groups were diseases of the respiratory system (15.5%) and neuro-muscular degenerative disorders (13.3%). These categories were merged to create four broad disorder groups (4.3) which formed the basis of the comparison of qualitative data.

Table 5 Distribution of illnesses between Intervention and Control groups

Illness category	Intervention group (n=30)	Control group (n=15)
Cancer	4	0
Heart disease	3	2
Liver disease	2	1
Kidney disease	1	2
Diseases of the respiratory system	6	1
Cystic fibrosis	4	5
Metabolic disorders	2	2
Neuro-muscular degenerative disorders	4	1
Profound physical and learning disability	4	1

The majority of families in both groups were from socio-economic group II (Table 6).

Table 6 Distribution of socio-economic status by father's occupation

Socio-economic group	Intervention group n=27 (%)	Control group n=13 (%)
I	3 (11.1)	2 (15.4)
II	12 (44.4)	6 (46.2)
III NM	3 (11.1)	1 (7.7)
III M	6 (22.2)	2 (15.4)
IV	1 (3.7)	1 (7.7)
Father unemployed	2 (7.4)	1 (7.7)

Three children were singletons, the remainder lived in a household with at least one sibling, 45% of whom were aged between 5 - 10 years. Two families had four children and 15 families had three children (including the index child). A small minority of children had adult siblings (5%).

The majority (97.5%) of children lived with two parents. Only one child lived within a lone parent family at the recruitment interview. All mothers in the control group and the majority (88.9%) in the intervention group were primary carers (Table 7).

Table 7 Role of primary care giver and parental situation at recruitment

	Intervention group n=27 (%)	Control group n=13 (%)
Primary carer – mother	24 (88.9)	13 (100)
Primary carer – father	1 (3.7)	0
Joint carer responsibility	2 (7.4)	0
Families comprising both parents	24 (88.9)	11 (84.6)
Families comprising mother and step-father	3 (11.1)	1 (7.7)
Lone parent families – mother	0	1 (7.7)

One fifth of children in the control group (20%) and one quarter in the intervention group (26.7%) were too young to attend school. However, the majority of each group (40.0% of intervention group and 66.7% of control group) attended main stream schools (Table 8). A quarter of children in the intervention group attended special needs schools while only two children from the control group required special educational facilities which could not be provided within a main stream environment.

Table 8 Distribution of children by type of school attended

School attended	Intervention group n=30 (%)	Control group n=15 (%)
Pre-school nursery	1 (3.3)	0
Mainstream LEA	12 (40.0)	10 (66.7)
Independent	1 (3.3)	0
Special	8 (26.7)	2 (13.3)
Too young to attend school	8 (26.7)	3 (20.0)

Table 9 Frequency of statement of special educational need

Statement of special educational need	Intervention group n=22 (%)	Control group n=12 (%)
Yes	9 (40.9)	3 (25.0)
No	13 (59.1)	9 (75.0)

Two fifths (40.9%) of children > 5 years of age in the intervention group and one quarter (25%) of the control group had been assessed by the Student Assessment Service and had a statement of special educational need in place (Table 9).

Table 10 Type of accommodation and place of residence

Housing type	Intervention group n=27 (%)	Control group n=13 (%)
Tied accommodation (employment related)	2 (7.4)	1 (7.7)
Public housing	6 (22.2)	2 (15.4)
Owner occupier	19 (70.4)	10 (76.9)
Within city boundaries	8 (29.6)	3 (23.1)
Rural area	19 (70.4)	10 (76.9)

Over two thirds of families owned their own home (73.7%) with almost three quarters of the sample families (73.7%) living outside the city (Table 10).

Table 11 Frequency of type of disability living allowance at recruitment

Type of allowance	Intervention group n=20 (%)	Control group n=7 (%)
Top	15 (75)	2 (28.6)
Middle	5 (25)	5 (71.4)
Mobility component	5 (25)	2 (28.6)

Twenty families in the intervention group were receiving DLA at recruitment. Of these, a large majority received the top rate for their child. One quarter of families received the middle rating while a further quarter received the mobility component. The majority of families in the control group received the middle rate of benefit on behalf of their child (Table 11).

Table 12 Frequency and distribution of perceived difficulties for families at recruitment

Problem area	Intervention group n=27 (%)	Control group n=13 (%)
Holidays in England	13 (48.0)	3 (23.1)
Holidays abroad	14 (51.9)	5 (38.5)
Day outings with family	10 (37.0)	2 (15.4)
Using public transport	9 (33.3)	2 (15.4)
Isolated from family	3 (11.0)	1 (7.7)
Isolated from friends	7 (25.9)	2 (15.4)

Families reported a number of difficulties in their daily and social lives which they perceived were attributable to their child's illness. Half of the intervention group described difficulties with taking holidays in England (48%) and abroad (51.9%). Only half the number of control group families reported difficulties

with using public transport (15.4%) and having days out as a family (15.4%) when compared with the intervention group (33.3% and 27.0% respectively). A minority of families in the intervention group felt isolated from their extended family (11.0%), although one quarter (25.9%) felt they were isolated from friends (Table 12).

Table 13 Frequency and distribution of extra expenditure at recruitment

Area of expenditure	Intervention group n=27 (%)	Control group n=13 (%)
Purchase of medical equipment	8 (29.6)	3 (23.1)
Purchase of aids to daily living	7 (25.9)	2 (15.4)
Modification to family home	7 (25.9)	3 (23.1)
Travel costs to hospital	6 (22.2)	4 (30.8)
Special food	2 (7.4)	0
Heating	1 (3.7)	0

Over one quarter of intervention group families reported purchasing medical equipment (29.6%); aids for daily living (25.9%) and expenditure concerned with making modifications to their homes (25.9%). Extra travel costs to attend hospital were also incurred by a considerable minority of families (intervention group 22.2% and control group 30.8%) (Table 13).

4.2.4 Functional ability of the children

More than half the children in the intervention group at recruitment experienced incontinence problems (58.6%); needed help with dressing (58.6%) and washing and bathing (60%), despite controlling for ability related to age and normal physical development. One third had difficulties with mobility (33.3%), eating and drinking (34.5%) and exhibited behavioural problems (33.3%), while a quarter of children had difficulty with expressing themselves verbally (26.7%). Almost half of control group children at the recruitment interview had problems with incontinence (46.7%), while two fifths experienced difficulties with eating and drinking (40%) and dressing (40%). One third of children needed assistance with washing and bathing (36.4%) and had difficulty with verbal communication (33.3%) (Table 14).

Table 14 Frequency of problems with functional ability at recruitment

Activity of daily living	Children in Intervention group (%)	Children in Control group (%)
Mobility*	10 (33.3) $_1$	2 (13.3) $_2$
Eating and drinking*	10 (34.5) $_3$	6 (40.0) $_2$
Continence*	17 (58.6) $_3$	7 (46.7) $_2$
Ability to turn self	4 (13.3) $_1$	1 (6.7) $_2$
Dressing*	17 (58.6) $_3$	6 (40.0) $_2$
Washing and bathing*	12 (60.0) $_4$	4 (36.4) $_5$
Communication*	8 (26.7) $_1$	5 (33.3) $_2$
Behaviour	10 (33.3) $_1$	1 (6.7) $_2$
Awareness of surroundings	4 (13.3) $_1$	0 (0) $_2$
Seizure pattern	4 (13.3) $_1$	1 (6.7) $_2$

* Age related activities 1: n=30 2: n=15 3: n=29 4: n=20 5: n=11

4.2.5 Caring interventions performed by parents

The most frequently reported caring intervention performed by parents in both groups was the administration of medicines. Seventy percent of intervention group and 86.7% of control group parents gave their child oral medicines; while one quarter of intervention group (26.7%) and one third (33.3%) of control group parents administered drugs via an inhaler or nebuliser. One quarter (26.7%) of the control group children required a complex drug regime while almost one third (30.0%) of parents in the intervention group were prepared to administer drugs in an emergency situation (e.g. epinephrine and diazepam) (Table 15).

The most frequently reported therapy intervention undertaken by parents concerned physiotherapy. One third (33.3%) of control group children required chest physiotherapy, while almost one quarter (23.3%) of intervention group children were given limb physiotherapy. More than one quarter (26.7%) of intervention group parents helped their children with speech therapy exercises (Table 15).

The only age related caring intervention concerned the need for constant family care. More than one third (35%) of children aged > 5 years in the intervention group (n=20) were reported to need 1:1 family care at all times.

Table 15 Frequency and distribution of caring interventions performed by parents at recruitment

Caring intervention	Children in Intervention group n=30 (%)	Children in Control group n=15 (%)
Oral medications	21 (70.0)	13 (86.7)
1:1 constant family care*	7 (35) n=20	2 (18.2) n=11
Administration of medication in an emergency	9 (30.0)	1 (6.7)
Administration of medication via inhaler / nebuliser	8 (26.7)	5 (33.3)
Speech therapy	8 (26.7)	2 (13.3)
Limb exercises / physiotherapy	7 (23.3)	2 (13.3)
IV, SC, PR medications	5 (16.7)	1 (6.7)
Chest physiotherapy	4 (13.3)	5 (33.3)
More than one person for moving & handling	4 (13.3)	1 (6.7)
Wears special clothes / appliance	3 (10.0)	1 (6.7)
Naso gastric / gastrostomy tube feeding	3 (10.0)	1 (6.7)
Naso/ oro/ tracheostomy suction	2 (6.7)	1 (6.7)
Complex medication regimen	2 (6.7)	4 (26.7)
Urinary catheter / ostomy	0	0
Treatment for pressure sore	0	0
Oxygen therapy	0	0

* Age related intervention

4.2.6 Expressed need for additional help

Table 16 Frequency and range of expressed need at recruitment

Number of items	Intervention group n=27 (%)	Control group n=13 (%)
0	0	2 (15.4)
1 – 5	18 (66.7)	9 (69.2)
6 – 10	6 (22.2)	2 (15.4)
11 – 21	3 (11.1)	0

At recruitment all families in the intervention group expressed a need for help with at least one item from the modified perceived needs scale (mean 5.2; range 1-16 items). Two thirds (66.7%) of the group reported needing help with between one and five items while almost a quarter (22.2%) expressed a need for additional help with between six and 10 items. A minority (11.1%) reported a need for help with between 11 and 16 items. Similar figures were obtained for the control group with just over two thirds (69.2%) expressing a need for additional help with between one and five items. However, two

families (15.4%) had no need for any additional help while the extent of need ranged from 0 to nine items (Table 16).

Table 17 Frequency of expressed need for additional help at recruitment

Need Domain	Item of help	Intervention group n=27 (%)	Control group n=13 (%)
Information	Availability of services and support	15 (55.5)	8 (61.5)
	Information about the specific condition	10 (37.0)	2 (15.4)
	Discussing the child's progress	7 (25.9)	1 (7.7)
Practical	Obtaining equipment / aids	9 (33.3)	2 (15.4)
	A link between hospital and home	9 (33.3)	0
	Transport related problems	7 (25.9)	1 (7.7)
	Nursing Assistance	6 (22.2)	0
	Improving the child's mobility	2 (7.4)	0
Social	Skilled child-minding	9 (33.3)	1 (7.7)
	Respite care	8 (29.6)	3 (23.1)
	Domestic help at home	5 (18.5)	3 (23.1)
	With family while resident in hospital	3 (11.1)	0
Emotional	Difficulties with family members e.g. siblings	8 (29.6)	1 (7.7)
	An informal support network	7 (25.9)	4 (30.8)
	Coming to terms with the condition	5 (18.5)	2 (15.4)
	Marital / partnership difficulties	1 (3.7)	1 (7.7)
Educational	Special education facilities / opportunities	9 (33.3)	2 (15.4)
	Link between hospital and school	6 (22.2)	2 (15.4)
Financial	Measures to improve housing	6 (22.2)	1 (7.7)
	Extra financial advice and / or help	6 (22.2)	1 (7.7)
	With the child in order to go out to work	3 (11.1)	0

The majority of families in both groups (intervention 55.0% and control 61.5%) expressed a need for additional help with information about the availability of services and support, with almost two fifths of the intervention group reporting a need for information about their child's illness (Table 17). One third of intervention group families (33.3%) expressed a need for help with the following areas: obtaining equipment and aids to daily living; a co-ordinator to act as a link between hospital services and their home; skilled child care and with access to educational facilities or opportunities for their

child. More than one quarter of intervention group families reported needing assistance with: discussing their child's progress (25.9%); problems with transport issues (25.9%); respite care (29.6%); emotional difficulties with family members (29.6%) and initiating an informal support network (25.9%). A large minority of families expressed a need for extra help with: nursing assistance in the home (18.5%); domestic help (18.5%); coming to terms with the illness (18.5%); a link between hospital services and their child's school (22.2%); financial advice (22.2%) and measures to improve their housing (22.2%). Although control group families expressed less need for additional help and support overall, a large minority reported needing assistance with respite care (23.1%); domestic help (18.5%) and developing an informal support network (30.8%).

4.3 The four disorder groups

Table 18 Distribution and composition of the four disorder groups of children in intervention and control groups.

Disorder group	Examples of diagnoses	Intervention group children (n=30)	Control group children (n=15)
Requirement for intensive medical resources	Severe asthma; food allergy and potential anaphylaxis; cancer.	9	1
Progressive degenerative disorders	Cystic fibrosis; Duchenne muscular dystrophy; spinal muscular atrophy; mucopolysaccharidosis; enzyme deficiency; Arginosuccinase deficiency; Beckwith Wiedermann syndrome.	10	8
Organ failure	Tetralogy of Fallot; pulmonary atresia; transposition of great arteries; Down's syndrome and pulmonary hypertension; congenital hepatic fibrosis; liver & renal transplantation; nephrotic syndrome; apnoea.	7	5
Profound disability	Rett syndrome; cerebral palsy with no independent mobility or verbal communication and tracheostomy.	4	1

As the frequency of some illnesses represented in the study was small (in two of the groups there was only one child with a particular diagnosis) the production of a detailed list of cases and their specific characteristics would increase the chance of families being identified. Therefore, in order to preserve family anonymity and safeguard against any breach of confidentiality a composite view of four disorder groups is offered (Table 18). This composition is perceived as a strength in that the focus for investigation in the qualitative component of the study lay with the needs and experiences of each disorder group as a whole rather than with the particular needs of individual families.

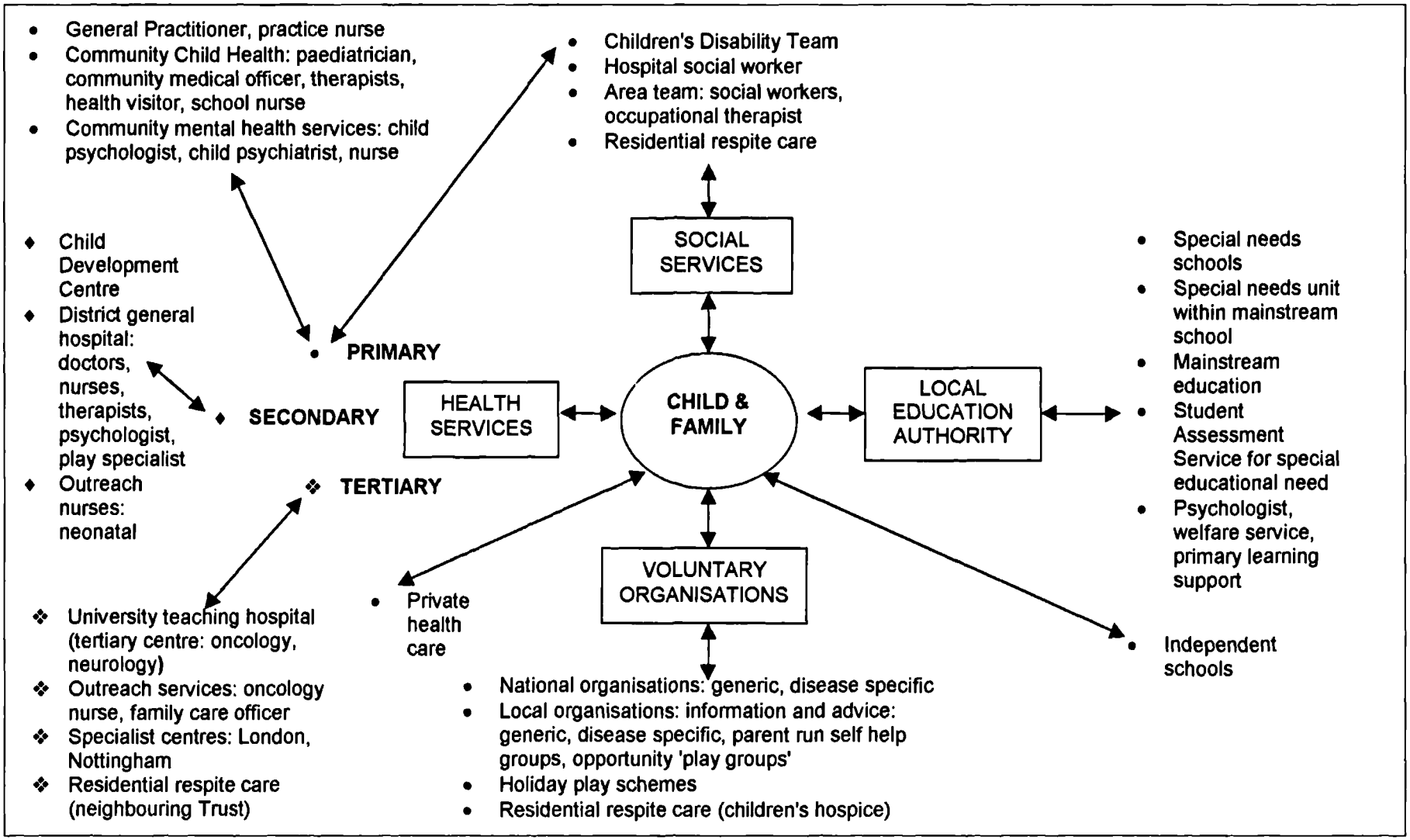
4.4 Service provision

A wide variety of services across the three statutory organisations and the voluntary sector comprised the global care provision for families in the study area. It is important to delineate this global care provision as it sets the scene for the caring contribution provided by the researcher in her intervention role. Figure 5 highlights the enormity of contacts with professionals which families could experience when faced with the experience of childhood LTI. Similar illustrations have been offered by NAHA (1988), Stein & Woolley (1990) and O'Neill and Rodway (1998). Tables 19 - 21 confirm the high number of professional contacts which families in the study had with the statutory organisations and in particular, although not unexpectedly, with an array of different health services.

4.4.1 Health Services

The University teaching hospital in the study area was a tertiary referral centre for oncology and neurological trauma which also served the local population as a District General Hospital (DGH). A children's oncology outreach nurse and a family care officer for children with neuro-degenerative disorders ministered to the entire region. The rarity of some LTIs meant that many families had their care managed in tertiary centres in London or Nottingham and shared care was practiced with the DGH and / or the GP.

Figure 5 Service provision in locality



Secondary health services (DGH) boasted three acute children's wards and a full range of medical, nursing (including a designated children's asthma nurse), therapy and support services such as play specialists. Two nurses outreached from the neonatal unit into the community. As the study commenced there were no generic CCNs outreaching from the DGH to care for children in their homes after hospitalisation. A multidisciplinary Child Development Centre bridged the gap between secondary and primary services for a minority of families caring for children with physical and learning disabilities, with a liaison health visitor undertaking some home assessments.

Primary care services included the GP and practice nurses at GP surgeries or health centres. However, it became apparent that, although families maintained contact with their GP for routine care such as for supplies of medications, queries or problems concerning their child's illness were frequently addressed directly to secondary or tertiary services. The Community Child Health Service headed by a consultant community paediatrician comprised a range of health visiting, school nursing and therapy services but as the study began lacked any form of CCN service for sick and disabled children. The District Nursing Service had on occasion provided care for children but none of the families in the study were in contact with a district nurse (DN) at the time of recruitment. The community mental health services provided a full range of in- and outpatient support to children and adults with mental health problems and also acted as a resource to other primary care professionals.

4.4.2 Social Services

Social workers based in nine area teams within the study area were available to assist families by providing information, practical and financial advice, although only a minority of families in the study reported having their own designated social worker. A social work department was based in the DGH to help the families of those children admitted to hospital with information and support. The Children's Disability Team offered a joint social services and

health service approach to working with children with disabilities and provided a home-based service. A variety of SSD respite care facilities were offered for children with special needs but were inappropriate for children with complex health and social care needs.

4.4.3 Local Educational Authority Services

A full range of statutory educational services were offered in the area: mainstream, special needs unit within a mainstream environment and special needs education. A home visiting service for pre-school children with special needs (portage) was run jointly with secondary health services. Other educational support included: an educational psychology service, an educational welfare service and a primary learning support service.

4.4.4 Voluntary organisations

Organisations were available which offered information and advice for families although families demonstrated a poor awareness of such services. Other organisations such as the Crossroads Care Attendant Scheme offered practical support to carers. Several Opportunity Groups offered families of children with special needs (0-5 years) an opportunity to socialise, share experiences and gain support from others in a similar situation. Holiday play schemes offered a service to some families for a short period during the long summer break, although most did not cater for children with complex health and social care needs.

The Children's Hospice situated in the study area provided respite, palliative and terminal care for children with LTIs. However, referrals were accepted from a wide geographical area which limited the organisation's ability to fully meet the needs of families in the study area. As residential respite care facilities were inadequate within the area some families obtained respite care in health service and voluntary sector (another children's hospice) establishments outside the geographical boundaries of the study.

4.5 Family contacts with services

Families reported a large number of contacts with organisations from the statutory services. Most frequently intervention group families were in contact with nine different services although the median number was eight contacts per family (range 0-14), while control group families reported a median of six present contacts.

Table 19 Frequency of present contacts with statutory services

Frequency of contacts	Intervention group n=27 (Std Dev)	Control group n=13 (Std Dev)
Median	8.0 (3.203)	6.0 (2.915)
Mode	9.0	5.0
Range of contacts	0 – 14	0 – 11

Table 20 Frequency of present contacts with health related statutory services

Frequency of contacts	Intervention group n=27 (Std Dev)	Control group n=13 (Std Dev)
Median	7.0 (2.557)	5.0 (2.634)
Mode	7.0	4.0
Range of contacts	0 – 12	0 – 10

Both groups of families reported a range of contacts with different health services (intervention 0-12; control 0-10), with intervention and control families reporting a median of seven and five contacts per family respectively.

Approximately half of both groups (intervention 48.1%; control 53.5%) were not in contact with any SSD. Of the remainder of the intervention group one quarter (25.9%) reported contact with one service, one fifth (18.5%) with two organisations and two families (7.4%) reported present contact with three different SSDs. The remaining 46.2% of control group families reported contact with one SSD.

The most frequent professional contact was with GPs with 92.6% of intervention group and 92.3% of control group families reporting contact.

Three quarters (77.8%) of intervention group families and just under half (46.1%) of control group families were in current contact with DGH hospital doctors although interestingly, almost two fifths (38.5%) of control group families but less than one fifth (18.5%) of intervention group families reported contact with tertiary service medical personnel. Families in both groups reported frequent contact with primary health care professionals with more than two thirds having contact with their HV and SN. Two fifths of intervention group families reported contact with community medical personnel: CMO (40.7%) and consultant paediatrician (37.0%). Control group families reported less contact with therapists than intervention group families (Table 21). Twice as many families in the intervention group had contact with a social worker which may account for the differences in number of contacts between the groups in Table 19.

Table 21 Frequency and distribution of present contact with members of statutory organisations

Professional group	Statutory organisation	Intervention group n=27 (%)	Control group n=13 (%)
General practitioner	Primary health	25 (92.6)	12 (92.3)
Hospital doctor	Secondary health	21 (77.8)	6 (46.1)
School nurse	Primary health	19 (70.4)	9 (69.2)
Health visitor	Primary health	16 (59.3)	6 (69.2)
Community medical officer(cmo)	Primary health	11 (40.7)	7 (53.8)
Community paediatrician	Primary health	10 (37.0)	2 (15.4)
Community physiotherapist	Primary health	9 (33.3)	3 (23.1)
Community speech therapist	Primary health	9 (33.3)	1 (7.7)
Hospital ward personnel	Secondary health	8 (29.6)	2 (15.4)
Social worker	Social services	8 (29.6)	2 (15.4)
Child development centre personnel	Multi-agency	7 (25.9)	1 (7.7)
Occupational therapist	Primary health	6 (22.2)	1 (7.7)
Hospital doctor	Tertiary health	5 (18.5)	5 (38.5)

Over half the control group families (53.9%) and two fifths of intervention group families (40.7%) reported current contact with at least one voluntary organisation which provided them with information. One quarter (25.9%) of intervention group families and almost two fifths (38.5%) of control families

reported receiving practical help from voluntary organisations. There was an even distribution of contacts between the two groups with generic and disease specific organisations although control group families reported a higher degree of contact with disease specific organisations. This probably reflected the large number (n=5) of children with CF in the control group, and the fact that many families were active participants in local branch or national CF Trust organisations.

Table 22 Frequency and distribution of present contact with voluntary organisations

Type of organisation	Intervention group n=27 (%)	Control group n=13 (%)
General	7 (25.9)	3 (23.1)
Disease specific	8 (29.6)	6 (46.2)
Information giving	11 (40.7)	7 (53.9)
Practical help	7 (25.9)	5 (38.5)

Figures do not add to 100% as families frequently reported contact with more than one organisation

4.6 Coping Health Inventory for Parents (CHIP)

Table 23 Frequency of mothers' CHIP scores outside the normative range by coping pattern

Coping pattern	Intervention group n=26 (%)	Control group n=7
Family integration	3 (11.5)	0
Social support	9 (34.6)	0
Medical communication	9 (34.6)	0

One third (34.6%) of intervention group mothers achieved scores below the normative range in the social support and medical communication coping patterns at recruitment, while a minority (11.5%) obtained a score outside the normative range in the coping pattern concerned with family integration. No mothers in the control group demonstrated scores outside the normal range in any of the three coping categories.

More than half the mothers in the intervention group obtained scores in the lower third or outside the normative range in all three of the coping patterns. Three respondents from the control group achieved a social support coping pattern score in the lower third of the normal range (Table 24).

Table 24 Frequency of mothers' CHIP scores outside normative range and in lower third of normative range scores (i.e. family <35; support <24; medical <13) by coping pattern.

Coping pattern	Intervention group n=26 (%)	Control group n=7 (%)
Family integration	13 (50.0)	2 (28.6)
Social support	16 (61.5)	3 (42.9)
Medical communication	14 (53.8)	1 (14.3)

Table 25 Frequency of mothers achieving CHIP scores outside the normative range by coping pattern and disorder group

Coping pattern	Disorder group 1 n=7	Disorder group 2 n=9	Disorder group 3 n=6	Disorder group 4 n=4
Family integration	1	1	1	0
Social support	3	2	2	0
Medical communication	1	4	2	2

Scores below the normative range were obtained in the social support coping pattern for three mothers of children requiring intensive medical resources (DG1). While almost half the mothers of children with progressive degenerative disorders (DG2) and profound disability (DG4) achieved a score outside the normal range in the medical communication coping category.

4.7 Summary

Eighty six of the 183 children nominated had some form of LTI. The largest groups represented were CF, neuro-degenerative disorders and diseases of the respiratory system. The nine categories of illness represented were merged to create four disorder groups which would form the focus of investigation for the qualitative component of the study. A degree of sample attrition was anticipated due to the delay between the end of the nomination process and the commencement of data collection. However, sample attrition due to health professional refusal to introduce the study to families was not expected. Twenty seven families (30 children) participated in the intervention

group and 13 families (15 children) participated as the control group.

The relative affluence of the study area was demonstrated in the large number of families from socio-economic groups I and II and the number of families owning their own homes. Contrary to the findings of other studies (e.g. Beresford 1995; While et al, 1996a) only one child lived within a lone parent family situation, although the majority of mothers were principal carers. The majority of children in both groups received some form of DLA. A large minority of children in the study were too young to attend school. Of the remainder, most were being educated within a mainstream school environment. Families reported difficulties in their daily and social lives, which they felt were attributable to their child's illness, for example, taking holidays, using public transport and having days out as a family. Families frequently reported extra expenditure on medical and household items related to their child's illness.

Assessment of functional ability demonstrated that more than half of the children experienced problems with activities of daily living such as, (in)continence, dressing, washing and bathing. Caring interventions performed by parents included: administration of drugs by a variety of routes, chest and limb physiotherapy and speech therapy. More than one third of children aged more than 5 years were reported as needing constant family care.

All families in the intervention group expressed a need for additional help with at least one item in the modified perceived needs scale at recruitment. Areas where most need for help were expressed were: information about the availability of services and support and about the disorder; equipment and aids to daily living; a coordinator to act as a link between hospital services and home; skilled childcare and access to educational facilities.

Coping strategies used by mothers in dealing with childhood LTI were assessed using the Coping Health Inventory for Parents (CHIP). A third of intervention group mothers obtained scores outside the normative range for

strategies concerned with social support and communication with medical and other personnel.

A wide variety of services across the statutory and voluntary sectors were provided in the study area and families reported a large number of contacts with professionals from all sectors. At recruitment no CCN services of either dominant model revealed by While and Dyson (In press), i.e. hospital outreach or community based services, were available to support families in their own homes.

Chapter 5 The Quasi-Experiment

5.1 Children's functional ability

Table 26 Mean functional ability scores by group and interview period

Group	Interview	Mean score (range)	Std Dev
Intervention	Time 1 (n=27)	3.6 (0-10)	3.3
	Time 2 (n=26)	3.7 (0-10)	3.2
	Time 3 (n=20)	3.3 (0-10)	3.5
Control	Time 1 (n=13)	2.6 (0-8)	2.7

Mean functional ability scores obtained for children in the intervention group ranged from 3.3 – 3.7 (possible score range 0-10) with the mean score for control group children somewhat less at 2.6 (range 0-8) (Table 26).

5.2 Caring interventions performed by parents

Table 27 Mean caring intervention scores by group and interview period

Group	Interview	Mean score (range)	Std Dev
Intervention	Time 1 (n=27)	2.9 (0-8)	2.1
	Time 2 (n=26)	2.9 (0-8)	2.3
	Time 3 (n=20)	3.1 (0-8)	2.1
Control	Time 1 (n=13)	2.5 (0-5)	1.2

Mean scores obtained for caring interventions performed by parents in the intervention group ranged from 2.9 – 3.1 (range 0-8), while control group children demonstrated a mean score of 2.5 (range 0-5).

5.3 Expressed need for additional help

5.3.1 Global need scores

At Time 1 (baseline at recruitment) all 27 families in the intervention group expressed a need for help with at least one item on the modified perceived needs scale (mean 5.2, range 1-16 items, Std Dev 3.8). There was a significant difference between these global need scores and those obtained from the 20 families who participated at Time 3 (mean 2.8, range 0-6, Std Dev 1.9, $z = 2.1483$, $p = 0.03$). However, as the sample of families at Time 3 was a subset of the original sample of 27 families this significant reduction

may have been due to differences brought about by sample attrition (Table 28).

Table 28 Mean global need scores by group and interview period

Group	Interview	Mean score (range)	Median	Std Dev	IQR
Intervention	Time 1 n=27	5.2 (1-16)	4.0	3.8	2-7
	Time 2 n=26	3.1 (0-12)	2.0	3.3	0.75-4
	Time 3 n=20	2.8 (0-6)	2.5	1.9	1-4
Control	Time 1 n=13	2.7 (0-9)	2.0	2.7	1-3

Families in the control group expressed a need for additional help with fewer items in the scale (mean 2.7, range 0-9 items). There was a significant difference between the global needs scores of the 27 intervention group families at recruitment (Time 1) and the global need scores of the 13 families in the control group ($z = 2.4925$, $p = 0.01$). However, no significant difference was demonstrated between the global need scores obtained from control group families and those obtained from the 20 intervention group families at Time 3 ($z = 0.6367$, $p = 0.52$).

Table 29 Matched pairs analysis of the mean global need scores of intervention group families for the 3 interviews.

Pairs of interviews	z	p
Time 1 x Time 2 (n=26)	-3.0355	<0.01**
Time 1 x Time 3 (n=20)	-3.5816	<0.01***
Time 2 x Time 3 (n=20)	-0.1420	0.88

** highly significant *** very highly significant

For the 20 families for whom there were data at both Time 1 (baseline at recruitment) and Time 3 interviews there was a very highly significant difference between the global need scores obtained at Time 1 (median = 4.0 IQR = 2-7) and at Time 3 (median = 2.8, IQR = 1-4, $z = 3.5816$, $p = <0.01$). This suggests that the change is not simply a function of sample attrition (Table 28), but reflects actual changes amongst participating families over time. A highly significant difference was also demonstrated in the comparison of mean global need scores obtained at Time 1 and Time 2 ($p=<0.01$) but not in the comparison of mean global need scores obtained at Time 2 and Time 3.

5.3.2 Need domain scores

Table 30 shows the six need domains ranked in order according to the degree of need expressed by the intervention group at Time 1 (baseline at recruitment). Families in both groups at Time 1 expressed most need for additional help in the informational need domain. Four fifths (81.5%) of intervention group families and more than two thirds (69.2%) of control families expressed a need for help with one or more of the three information related items in the perceived needs scale. Just less than two thirds (63.0%) of the intervention group expressed a need for more help with one or more of the five items in the practical need domain but less than a quarter (23.1%) of the control group expressed a need in this area.

Table 30 Frequency of expressed need for additional help with one or more items by need domain.

Need domain (n= number of items from scale)	Intervention group Time 1 n=27 (%)	Intervention group Time 2 n=26 (%)	Intervention group Time 3 n=20 (%)	Control group Time 1 n=13 (%)
Informational (n=3)	22 (81.5)	8 (31.0)	6 (30.0)	9 (69.2)
Practical (n=5)	17 (63.0)	10 (38.5)	7 (35.0)	3 (23.1)
Social (n=4)	15 (55.5)	9 (34.6)	8 (40.0)	5 (38.5)
Educational (n=2)	13 (48.1)	9 (34.6)	7 (35.0)	4 (30.8)
Emotional (n=4)	11 (40.7)	9 (34.6)	7 (35.0)	5 (38.5)
Financial (n=3)	11 (40.7)	8 (31.0)	9 (45.0)	1 (7.7)

More than half of intervention group families (55.5%) and over one third of control families (38.5%) reported needing extra help with one or more of the four items in the social need domain. In addition, almost half the intervention group (48.1%) but less than one third (30.8%) of control group families expressed unmet need with one or both items in the educational need domain. Interestingly, only two fifths of each group reported a need for additional help with one or more of the four items in the emotional need

domain. The largest discrepancy between the groups at Time 1 was observed in the financial need domain. Two fifths of intervention group families (40.7%) but only one family (7.7%) in the control group expressing a need for more help with one or more of the three items related to family finances (Table 30).

5.3.3 Constancy of need

The frequency of intervention group families expressing a need for more help with one or more items in all need domains reduced at Time 2 with the greatest reduction in need seen in the informational need domain. Nevertheless, almost one third of families continued to report unmet need in all of the need domains at Time 2. Analysis of frequency of expressed need at Time 2 and Time 3 highlights a constancy of unmet need for one third to two fifths of intervention group families. Comparison of serial data may be problematic as these are frequencies of an unrelated sample and thus any differences seen may have been brought about by sample attrition.

5.3.4 Relationships between need domain scores

Tables 31-33 show matched pairs analysis of intervention group mean need scores for the six need domains between Time 1 (baseline at recruitment) and Time 2; Time 1 and Time 3 and Time 2 and Time 3.

Table 31 Intervention group Time 1 and Time 2 (matched pairs n = 26) mean need scores by domain.

Need domain	Mean score Time 1 (SD)	Median Time 1 (IQR)	Mean score Time 2 (SD)	Median Time 2 (IQR)	z	p
Informational	1.2 (0.8)	1 (1-2)	0.4 (0.7)	0 (0-1)	-2.7806	<0.01**
Practical	1.2 (1.2)	1 (0-2)	0.65 (1.0)	0 (0-1)	-2.1340	0.03*
Social	0.9 (1.1)	1 (0-1)	0.6 (0.9)	0 (0-1)	-1.9876	0.04*
Emotional	0.8 (1.1)	0 (0-2)	0.5 (0.8)	0 (0-1)	-1.3628	0.17
Educational	0.6 (0.6)	0 (0-1)	0.5 (0.7)	0 (0-1)	-0.7060	0.48
Financial	0.6 (0.7)	0 (0-1)	0.5 (0.8)	0 (0-1)	-0.6290	0.52

* significant ** highly significant

Significant reductions in mean scores in the informational (p=<0.01), practical (p=0.03) and social (p=0.04) need domains were demonstrated between Time 1 and Time 2.

Table 32 Intervention group Time 1 and Time 3 (matched pairs n = 20) mean need scores by need domain.

Need domain	Mean score Time 1 (SD)	Median Time 1 (IQR)	Mean score Time 3 (SD)	Median Time 3 (IQR)	z	p
Informational	1.2 (0.8)	1 (1-2)	0.3 (0.5)	0 (0-1)	-3.5162	<0.01***
Practical	1.2 (1.2)	1 (0-2)	0.4 (0.6)	0 (0-1)	-3.1798	<0.01**
Social	0.9 (1.1)	1 (0-1)	0.65 (0.9)	0 (0-1)	-2.1917	0.02*
Emotional	0.8 (1.1)	0 (0-2)	0.45 (0.7)	0 (0-1)	-1.6474	0.09
Educational	0.6 (0.6)	0 (0-1)	0.5 (0.8)	0 (0-1)	-0.5606	0.57
Financial	0.6 (0.7)	0 (0-1)	0.5 (0.6)	0 (0-1)	-0.5916	0.55

* significant ** highly significant *** very highly significant

There were also significant differences in informational (p=<0.01), practical (p=<0.01) and social (p=0.02) mean need domain scores between Time 1 and Time 3 (Table 32).

Table 33 Intervention group Time 2 and Time 3 (matched pairs n = 20) mean need scores by need domain.

Need domain	Mean score Time 2 (SD)	Median Time 2 (IQR)	Mean score Time 3 (SD)	Median Time 3 (IQR)	z	p
Informational	0.4 (0.7)	0 (0-1)	0.3 (0.5)	0 (0-1)	-1.0662	0.28
Practical	0.65 (1.0)	0 (0-1)	0.4 (0.6)	0 (0-1)	-0.9336	0.35
Social	0.6 (0.9)	0 (0-1)	0.65 (0.9)	0 (0-1)	-0.2548	0.79
Emotional	0.5 (0.8)	0 (0-1)	0.45 (0.7)	0 (0-1)	-0.2801	0.77
Educational	0.5 (0.7)	0 (0-1)	0.5 (0.8)	0 (0-1)	-0.2535	0.79
Financial	0.5 (0.8)	0 (0-1)	0.5 (0.6)	0 (0-1)	-0.2097	0.83

However, there were no significant differences seen in the comparison of mean need domain scores between Time 2 and Time 3 (Table 33).

5.4 Four disorder groups comprising the intervention group

5.4.1 Children's functional ability

Table 34 Frequency of mean functional ability scores by disorder group

Disorder group (DG)	Time 1 mean scores (SD)	Time 2 mean scores (SD)	Time 3 mean scores (SD)
Intensive medical resources (DG1)	n=8 0.9 (1.1)	n=7 1.9 (1.5)	n=4 0.8 (1.0)
Progressive degenerative (DG2)	n=9 2.6 (1.8)	n=9 2.8 (2.3)	n=7 2.0 (1.8)
Organ failure (DG3)	n=6 3.3 (2.7)	n=6 3.7 (3.1)	n=6 3.2 (3.3)
Profound disability (DG4)	n=4 9.3 (1.0)	n=4 9.3 (0.5)	n=3 9.7 (0.6)

Children requiring intensive medical resources (DG1) demonstrated the lowest functional ability scores. Unsurprisingly, the highest scores were obtained for children with profound disability (DG4) indicating dependence on others for activities of daily living (Table 34).

5.4.2 Caring interventions performed by parents

Parents of children in disorder groups 1, 2 and 3 carried out a mean of 2.1 - 2.3 caring interventions, while parents of children with profound disabilities (DG4) carried out more than three times as many interventions (6.7 - 7.3 mean scores) (Table 35).

Table 35 Frequency of mean caring intervention scores by disorder group

Disorder group (DG)	Time 1 mean scores (SD)	Time 2 mean scores (SD)	Time 3 mean scores (SD)
Intensive medical resources (DG1)	n=8 2.5 (1.1)	n=7 2.0 (1.5)	n=4 2.5 (0.6)
Progressive degenerative (DG2)	n=9 2.0 (1.1)	n=9 2.2 (1.2)	n=7 2.7 (1.3)
Organ failure (DG3)	n=6 1.8 (1.3)	n=6 2.3 (2.0)	n=6 2.3 (2.2)
Profound disability (DG4)	n=4 7.3 (1.0)	n=4 7.0 (1.2)	n=3 6.7 (1.5)

5.4.3 Global need scores

Table 36 Frequency of mean global need scores by interview and disorder group

Disorder group (DG)	Time 1 mean scores (SD)	Time 2 mean scores (SD)	Time 3 mean scores (SD)
Intensive medical resources (DG1)	n=8 4.7 (4.8)	n=7 3.6 (3.1)	n=4 2.2 (2.6)
Progressive degenerative (DG2)	n=9 4.8 (3.4)	n=9 2.9 (3.6)	n=7 2.6 (1.3)
Organ failure (DG3)	n=6 4.7 (3.0)	n=6 1.8 (1.6)	n=6 2.3 (1.7)
Profound disability (DG4)	n=4 8.0 (3.7)	n=4 4.5 (5.1)	n=3 5.0 (1.7)

Disorder groups 1, 2 and 3 at Time 1 (baseline at recruitment) had mean global need scores of 4.7 - 4.8. Children with profound disability (DG4) demonstrated a mean need score of 8.0, almost twice that of the other groups. The mean need scores for children requiring intensive medical

resources (DG1) and progressive degenerative disorders (DG2) reduced at Time 2 and continued to fall at Time 3 to 2.2 and 2.6 respectively. Children with organ failure (DG3) and profound disability (DG4) demonstrated a considerable reduction at Time 2 with a slight rise to 2.3 and 5.0 at Time 3. However, the reduction in mean global need scores seen in DGs 1, 2 and 4 may have been brought about by changes due to sample attrition (Table 36).

5.4.4 Differences between disorder groups

Table 37 Analysis of differences in functional ability, caring intervention and global need scores between disorder groups (Kruskal-Wallis 1-way ANOVA)

Time	Intervention group	Variable	Chi-square	p
1	n=27	Functional ability	13.6648	<0.01**
2	n=26	Functional ability	10.9875	0.01*
3	n=20	Functional ability	8.9442	0.03*
1	n=27	Caring intervention	11.2295	0.01*
2	n=26	Caring intervention	10.1165	0.01*
3	n=20	Caring intervention	7.5496	0.05*
1	n=27	Global need	3.2568	0.35
2	n=26	Global need	1.7528	0.62
3	n=20	Global need	4.2009	0.24

* significant ** highly significant (Degrees of freedom = 3 in all cases)

Analysis of functional ability and caring intervention scores showed significant differences between the four disorder groups comprising the intervention group. No differences were demonstrated between the groups in their level of expressed need (global need scores).

5.4.5 Relationships between global need scores

Tables 38-41 show the matched pairs analysis of the mean global need scores for each of the four disorder groups at Time 1 and Time 2, Time 1 and Time 3 and Time 2 and Time 3.

Table 38 Matched pairs analysis of mean global need scores: requiring intensive medical resources (DG1)

Pairs of interviews	z	p
Time 1 x Time 2 (n=7)	-1.0483	0.29
Time 1 x Time 3 (n=4)	-1.8257	0.06
Time 2 x Time 3 (n=4)	-1.6036	0.10

No significant differences were demonstrated between the three pairs of global need scores for the group of children requiring intensive medical resources (DG1), although significance was almost achieved between Time 1 (baseline at recruitment) and Time 3 scores.

Table 39 Matched pairs analysis of mean global need scores: Progressive degenerative disorders (DG2)

Pairs of interviews	z	p
Time 1 x Time 2 (n=9)	-1.4003	0.16
Time 1 x Time 3 (n=7)	-2.3664	0.01*
Time 2 x Time 3 (n=7)	-0.9435	0.34

* significant

A significant difference was demonstrated between global need scores at Time 1 and Time 3 for children with progressive degenerative disorders (DG2).

Table 40 Matched pairs analysis of mean global need scores: Organ failure (DG3)

Pairs of interviews	z	p
Time 1 x Time 2 (n=6)	-2.0226	0.04*
Time 1 x Time 3 (n=6)	-1.7529	0.07
Time 2 x Time 3 (n=6)	-0.6290	0.52

* significant

Analysis of the global need scores of children with organ failure (DG3) showed a significant difference between scores at Time 1 and Time 2 but not in the comparison of Time 1 and Time 3 scores.

No significant differences were demonstrated between any pairs of scores obtained for children with profound disabilities (DG4) (Table 41).

Table 41 Matched pairs analysis of mean global need scores: Profound disability (DG4)

Pairs of interviews	Z	p
Time 1 x Time 2 (n=4)	-1.6036	0.10
Time 1 x Time 3 (n=3)	-1.6036	0.10
Time 2 x Time 3 (n=3)	-0.4472	0.65

5.4.6 Relationships between global need scores by need domain

Tables 42-45 show matched pairs analysis of the mean need domain scores for each of the four disorder groups between Time 1 and Time 2, Time 1 and Time 3 and Time 2 and Time 3.

Table 42 Matched pairs analysis of mean need domain scores: Requiring intensive medical resources (DG1)

	Time 1 x Time 2 (n=7)		Time 1 x Time 3 (n=4)		Time 2 x Time 3 (n=4)	
Need domain	z	p	z	p	z	p
Educational	-0.6742	0.50	-0.5345	0.59	0.0000	1.00
Emotional	-0.5477	0.58	-0.0000	1.00	-1.0000	0.31
Financial	-0.2673	0.78	-1.0000	0.31	-1.3416	0.17
Informational	-0.9439	0.34	-1.6036	0.10	-0.8018	0.42
Practical	-0.8018	0.42	-1.3416	0.17	-1.0000	0.31
Social	-0.5345	0.59	-1.3416	0.17	-1.3416	0.17

There were no significant differences noted between the three pairs of mean need domain scores in any of the six domains for children requiring intensive medical resources (DG1) (Table 42).

Table 43 Matched pairs analysis of mean need domain scores: Progressive degenerative disorders (DG2)

	Time 1 x Time 2 (n=9)		Time 1 x Time 3 (n=7)		Time 2 x Time 3 (n=7)	
Need domain	z	p	z	p	z	p
Educational	-0.5345	0.59	-0.5345	0.59	-0.5345	0.59
Emotional	-1.6036	0.10	-1.2780	0.20	-1.3416	0.17
Financial	-0.1048	0.91	0.0000	1.00	-0.6742	0.50
Informational	-1.1832	0.23	-2.0226	0.04*	-1.3416	0.17
Practical	-0.5916	0.55	-2.0226	0.04*	-0.7303	0.46
Social	-1.8257	0.06	-1.8257	0.06	0.0000	1.00

* significant

A significant difference was also demonstrated in the informational need domain mean scores between Time 1 and Time 2 and Time 1 and Time 3 for children with organ failure (DG3) (Table 44).

Table 44 Matched pairs analysis of mean need domain scores: Organ failure (DG3)

	Time 1 x Time 2 (n=6)		Time 1 x Time 3 (n=6)		Time 2 x Time 3 (n=6)	
Need domain	z	p	z	p	z	p
Educational	0.0000	1.00	0.0000	1.00	0.0000	1.00
Emotional	-0.9129	0.36	-0.7303	0.46	-1.0954	0.27
Financial	-1.3416	0.17	-0.5345	0.59	-1.6036	0.10
Information	-2.2014	0.02*	-2.0226	0.04*	-0.5345	0.59
Practical	-1.2780	0.20	-1.6036	0.10	-0.5345	0.59
Social	-1.3416	0.17	0.0000	1.00	-1.3416	0.17

* significant

Table 45 Matched pairs analysis of mean need domain scores: Profound disability (DG4)

	Time 1 x Time 2 (n=4)		Time 1 x Time 3 (n=3)		Time 2 x Time 3 (n=3)	
Need domain	z	p	z	p	z	p
Educational	0.0000	1.00	0.0000	1.00	0.0000	1.00
Emotional	-1.3416	0.17	-1.3416	0.17	-1.0000	0.31
Financial	0.0000	1.00	-1.0000	0.31	-0.5345	0.59
Information	-1.6036	0.10	-1.6036	0.10	-1.0000	0.31
Practical	-1.8257	0.06	-1.6036	0.10	-0.5345	0.59
Social	-1.0000	0.31	-0.8018	0.42	0.0000	1.00

As with the analysis of the global need scores no significant differences were demonstrated between any of the pairs of mean need domain scores obtained from families caring for children with profound disabilities (DG4) (Table 45).

5.5 Nurse-led interventions

As anticipated nurse-led interventions were initiated on three levels: 1) on an individual family basis; 2) projects concerning common issues reported by families and 3) non-patient related activities such as strategic and policy planning for the future development of the CCN service.

During the 16 months of the data collection period (01.04.94 - 14.07.95) all direct and indirect contacts with families as well as non-patient related activities undertaken by the researcher were recorded. This was consistent with the Community NHS Trust's operational procedures for other community nurses (DNs, HVs and SNs). A mean of 11% of time (hours) available each month was spent conducting family interviews (range 1-27%), while family related care and interventions accounted for a further 45% (mean) of time available. Time spent with aspects of the research (methodology and analysis) accounted for the largest proportion of non-patient related activity (mean 27% of available time per month), with a further 18 % (mean) of time available per month spent on administration and strategic and policy planning. During the data collection period the researcher carried out 241 visits with families in the intervention group, predominately in the family home, but visits were also made to children in schools, nurseries and respite care facilities (Table 46).

Table 46 Frequency of nurse-led interventions by activity

Researcher activity	Mean percentage (range) of total time available each month
Home visit: family interview	11 (1-27)
Home visit: nursing care, care planning, advice and support	17 (9-28)
Family care planning	22 (8-36)
Family telephone contact	3 (1-4)
Liaison visits / training of others (statutory and non statutory professionals)	3 (0-10)
ALL DIRECT AND INDIRECT FAMILY CARE	**56***
Research / study	27 (11-46)
General administration for CCN service (incl. equipment loan service)	8 (5-11)
Meetings (with statutory and voluntary agencies) strategic and policy planning	10 (1-16)
ALL NON-PATIENT RELATED ACTIVITY	**45***

* adds to 101% as figures have been rounded

5.5.1 Interventions with families

Key interventions initiated by the researcher within the informational need domain related to providing families with information specific to their child's

illness or disability. Several families used the interviews as a chance to confirm their understanding of their child's problems, treatments and future plans. The foremost request for help to which the researcher responded concerned advice about available services to enable them in their caring role.

Within the practical domain families expressed a need for a link and better information exchange between them and the various provider agencies with which they had contact. Interventions aimed to enhance communication processes at the interfaces between the different services. For example, by co-ordinating outpatient appointments, one family whose child's care was shared between a tertiary centre in London and the local DGH, was enabled to attend hospital only once rather than three times in the space of as many weeks.

One third of families in the intervention group reported a need for help with obtaining specialist medical equipment and aids to daily living (Table 17) or with having their equipment adequately maintained. The researcher approached local charities, for example, Action for Sick Children and CF Help to provide items for individual children. An equipment loan service was established within the confines of the CCN service to facilitate the safe and effective management of equipment and aids.

Within the social need domain skilled child minding and respite care were the principal areas of need expressed by families (Table 17). Interventions included liaison with agencies which provided respite care, both within and outside the study area, to maximise the services provided to individual families. Applications to charities organising holidays were made on behalf of families and were successful for several children. These opportunities offered respite to the family and an enjoyable time was had by the young people involved. Another example concerned the negotiation of funds (from an SSD) for three hours skilled child minding each week (for a six month period) for a young child. This small amount of regular relief was instrumental in reducing family stress considerably.

Collaboration with the Children's Disability Team (Figure 5) led to the preparation of jointly funded (by health and social services) respite care packages for children with complex health and social care needs. This involved detailed assessment of individual families to determine how best to meet their needs. A respite care package for one child involved five different agencies. In some cases it may be inappropriate for a child to meet so many different professionals, but in this instance it was considered essential to provide the family with the level of support needed to enable them to continue caring for their child at home.

Difficulties with other family members, particularly healthy siblings, were a cause for concern for parents within the emotional need domain. Siblings and grandparents were given time to talk through issues which were important to them. For example, several older siblings were concerned about the symptoms of degenerative conditions, and two sets of grandparents received instruction about treatments and emergency procedures so that they could share the burden of care with their children.

Several children required caring interventions during the course of a school day. Training was initiated with school staff with such interventions as naso- and tracheo-pharyngeal suction, enteral feeding and the administration of emergency procedures including oxygen therapy. This relieved the pressure on families of providing such training themselves.

Interventions within the financial need domain mainly related to supporting parents with their DLA (re)applications. For one family considerable liaison took place with an SSD occupational therapist in response to their need for measures to improve their housing for which they needed financial assistance.

5.5.2 Intervention projects

5.5.2.1 'Useful Numbers' information leaflet

More than half the families participating in the study expressed the need for more help with information regarding available services and types of support in the study area (Table 17). The researcher co-ordinated a project to explore ways in which parents' access to information could be improved and to decide what action could be taken. Meetings with representatives from all service areas (Figure 5) were held over a period of seven months. A range of ideas were discussed including the nature and level of information which should be provided, how and by whom it should be collated and offered, as well as the differing needs of families at disclosure of the diagnosis, throughout the illness trajectory and at times of crisis. A leaflet for all parents of children with chronic illness, disability or special needs was produced which gave a brief description of initial contact points to help parents access local services and sources of further information about the range of help which was available.

A pilot leaflet was circulated to selected parents, providers and voluntary organisations with a brief questionnaire asking for their comments, views and ideas. Two hundred postal questionnaires were distributed yielding a response rate of 44%. A wide range of positive comments and suggestions for improvement were received. These were discussed and appropriate amendments made. Following publication the leaflet was disseminated widely via statutory and voluntary agencies. Those who participated in this multi-professional initiative agreed that working together had been a positive and extremely useful learning experience, and a good way to network.

5.5.2.2 Medical equipment loan service

In accordance with good practice (Kohler & Radford, 1985, Chambers et al, 1989), a medical equipment lending service was established by the researcher, for both short- and long-term loans. Proper safety procedures

and provision for regular servicing and maintenance were established under the management of the CCN service

'The Children's Home Support Trust Fund' was created to receive donations and from which to purchase equipment. Although this perpetuated the practice of purchasing medical equipment from charitable sources it was agreed that this should continue until a clear line of provision could be established within the purchasing contracts from the commissioners of health care. Items purchased during the course of the study included: nebulisers, suction machines, syringe drivers, oxygen cylinder head flow meters, a portable pulse oximeter and two tipping frames for use by children with CF.

5.5.2.3 Home-based respite care

Home-based respite care was offered to a purposive sample of four intervention group families. The aim was to provide small amounts of regular and flexible respite care in the home environment to children with complex health and social care needs. This pilot service was not a replacement for residential respite care but complementary to the care and support already provided to these families. Children's nurses were recruited on a bank basis and three hours of care per week was offered to suit family need. Monthly support meetings coordinated by the researcher were held for the nurses who were also encouraged to have weekly telephone contact with the researcher or the Children's Disability Team. Evaluation from the families' perspective was undertaken during the Time 2 and Time 3 interviews.

It is noteworthy that difficulties were experienced in the recruitment of children's nurses able to offer time when families requested most help (4 - 7 p.m.). Throughout the pilot scheme two nurses felt that they were not using their skills to the full as there was little change in the work routine from week to week. A potential solution was to tap the resources of the local branch of the Crossroads Care Attendant Scheme. The local scheme were keen to extend their remit to the carers of sick and disabled children when approached by the researcher, and were successful in securing a small grant

from 'Children in Need' to do this. Carers were introduced to three children and their families and training and support with specific health care interventions was given by the child's parents and Children's Disability Team.

The decision to recruit trained nurses for this pilot scheme was not completely effective, although at the time professional, managerial and administrative expectations led to the recruitment of Registered Sick Children's Nurses into an existing bank nursing system designed for adult care. In support of trained nurses as carers, however, one father expressed:

> ".....we have the nurse coming in now - that's excellent which is respite care for us and good nursing for (child). It's both things". DG4 F2 T2

All four families appreciated the input from trained nurses, however, two families particularly valued the informality of untrained carers.

5.5.2.4 Training programme for schools: Food allergy and potential anaphylaxis

The need for a comprehensive training programme for schools was stimulated by the problems of three families caring for children with serious food allergies, who were at risk of a potentially fatal anaphylactic reaction requiring constant access to injectable epinephrine. Three children with this disorder and their families participated in the intervention group. However, after the study had commenced a further 20 children were identified and prescribed epinephrine by the local specialist allergy clinic for use if an emergency situation should arise (Ewan, 1996). This precipitated the need for the introduction of individualised care plans in schools and nurseries (Vickers et al, 1997). The aim of the programme was to bridge the gaps between primary and secondary health services, LEA personnel, the child and family.

The programme comprised four elements:

1) An individualised written plan designed by the researcher concerning procedures to follow should an allergic reaction occur, including particular

symptoms, dosages of medication to be given and the procedure to summon help from emergency services

2) A practical training session given by the researcher and consultant community paediatrician, attended by parent(s), school staff and SN. Information on prevention, identification and the procedure to follow should a reaction occur, and a demonstration on the safe administration of inhaled and injectable epinephrine was included.

3) Written confirmation of the session, naming participants who demonstrated practical competence.

4) Annual refresher session.

Discussion with the LEA and representatives of local teachers' unions allayed anxieties expressed by teachers about not being indemnified by the LEA and resulted in the assurance that staff would be supported if they undertook appropriate training. Concerns were further diminished in the knowledge that with thoughtful prevention the chances of a child having a reaction requiring the administration of an injection were extremely small. Parental anxiety was drastically reduced as the responsibility of providing information was lifted from them.

5.5.3 Strategic and operational planning

The researcher spent a mean of 10% of time (hours) available each month (Table 46) in strategic planning meetings related to the development of the CCN service, collaborating with SSD personnel regarding respite care and with LEA professionals concerning the anaphylaxis training programme.

Needs expressed by families contributed to a review of the interface between health and social care which recognised the increasing dependency of children as well as adults, as users of health and social care services in both residential and domiciliary settings. Issues associated with the performance of health care interventions by non-health professionals included questions of accountability, legal liability and employee indemnity, resource implications,

practicalities of providing appropriate training, and safety of the delegation process.

Liaison with the Children's Disability Team to determine the most appropriate approach regarding the provision of respite care for children with significant care demands was considerable. This collaboration produced information concerning respite care deficits of all families in the area including those with chronic non-progressive disorders who were not involved in the research. This information contributed to continuing discussions between health and social services commissioners to decide how respite care deficiencies in the study area could best be rectified.

Collaboration with LEA professionals took place in response to needs expressed by families. In particular, the needs of three intervention group families caring for children with allergy problems were instrumental in the development of the district wide training programme for schools by health professionals. Discussions to resolve problems experienced by families and professionals contributed to the development of a Medication in Schools Policy (Cambridgeshire LEA, 1995).

5.5.4 Nurse-led interventions by disorder group

The total number of home visits to families of children requiring intensive medical resources (DG1) and children with progressive degenerative disorders (DG2) was 42 with the duration of visits totalling 62 and 74 hours respectively. The mean number of visits per family (10.3) in the group of children with organ failure (DG3) was twice the number for those to families in disorder groups 1 and 2, despite the group comprising fewer families. However, the duration of the visits was slightly less when compared with the duration of visits for disorder group 2. Interestingly, analysis of researcher activity for children with profound disability (DG4) showed more than twice the total number of home visits when compared with disorder groups 1 and 2. The mean number of visits per family in disorder group 4 computed to 23.8,

more than four times the mean rate for groups 1 and 2, with 111 hours of time spent with these families during the study period (Table 47).

Table 47 Frequency of home visits by researcher by disorder group

Disorder group	Total number of visits to group	Mean number of visits per family (range)	Total duration of visits for group (hours)
Intensive medical resources (DG1) n=8	42	5.2 (2-11)	62
Progressive degenerative (DG2) n=9	42	5.8 (3-10)	74
Organ failure (DG3) n=6	62	10.3 (6-25)	69.5
Profound disability (DG4) n=4	95	23.8 (4-39)	111

In addition, two families in the pilot study received a total of 138 home visits from the researcher which amounted to 143 hours of direct family care intervention time. These figures are included in the analysis of researcher activity (Table 46) but not in the analysis of individual disorder group visits (Table 47).

5.6 Exploration of nurse-led interventions

Analysis of interventions undertaken with families revealed the use of a variety of professional nursing skills (Table 48). However, three themes in particular pervade the interventions above and can be viewed as 'enablers' to an effective service. i) A problem-solving approach to care rather than one which is task or disease orientated. ii) Family-centred care i.e. care which focuses on the wellbeing of all family members not just the sick or disabled child. iii) The development of a supportive partnership relationship with the family.

Table 48 Nurse-led interventions and key aspects of the CCN role pertaining to the family

Intervention	Key aspects of role
Provision of information	♦ Expert knowledge regarding: available services and specific diseases ♦ Knowing where and how to access information ♦ Knowing boundaries of own knowledge i.e. when to say I don't know but I'll find out ♦ Problem solving and developing supportive partnership ♦ Enabling ♦ Empowering
Individual counselling / support to immediate and extended family	♦ Counselling ♦ Partnership approach ♦ Supportive relationship ♦ Interpersonal skills i.e. listening, empathy
Teaching regarding practical caring interventions to immediate and extended family; and to health and non-health professionals	♦ Educating ♦ Technical expertise ♦ Sharing of information ♦ Helping find solutions to daily problems
Co-ordination of family care within and across health and other organisations. Provision of a link between family and services	♦ Key-working ♦ Co-ordinating ♦ Information exchange at service interfaces ♦ Inter-professional skills i.e. networking, liaison and communication skills
Recognition of family problems and joint care planning with other organisations (health, SSDs, schools) to find solutions e.g. preparation of jointly funded respite care packages for child with complex needs	♦ Multi-professional working ♦ Teaching ♦ Inter-professional skills i.e. listening to expertise of other professionals ♦ Crossing organisational and professional boundaries
Visiting tertiary centre managing child's care	♦ Acquisition of specialist information and technical skills ♦ Networking ♦ Communicating
Giving home telephone number	♦ 24 hour accessibility (small number of occasions, not routine)

Table 49 Nurse-led interventions and key aspects of the CCN role pertaining to multi-professional working

Interventions	Key aspects of role
Participation in multi-professional meetings with provider services	♦ Communication skills ♦ Leadership skills ♦ Inter-professional skills ♦ Collaboration
Negotiation with charitable organisations as sources of funding	♦ Communication and negotiation skills ♦ Problem-solving
Negotiation with voluntary organisations as sources of practical help	♦ Communication and negotiation skills ♦ Problem-solving ♦ Collaboration
Purchase and management of medical equipment	♦ Knowledge of policy and budgetary procedures, resource implications ♦ Awareness of safety procedures ♦ Policy development
Establishment and maintenance of Trust Fund	♦ Knowledge of policy and budgetary procedures
Working alongside other organisations regarding management issues	♦ Problem-solving i.e. respite care and use of non-parent carers and accountability issues ♦ Collaboration ♦ Negotiation skills ♦ Crossing professional and organisational boundaries
Establishment of training programme for schools	♦ Liaison with professionals from other organisations ♦ Appreciation of legal liability and employee indemnity when delegating to non-health professionals
Recruitment of qualified nurses into bank scheme	♦ Recruitment and management of staff ♦ Leadership qualities ♦ Clinical supervision ♦ Understanding of resource implications
Multi-professional meetings with commissioners of health and social care services	♦ Communication skills ♦ Research skills i.e. provision of evidence of need ♦ Understanding of resource implications
Dissemination of research findings – evidence of need	♦ Presentation skills (participation in local and national conferences)

Analysis of interventions undertaken within a multi-professional framework also revealed the use of a variety of skills (Table 49). The principal theme underpinning these aspects of the CCN role is the recognition of the need for a collaborative working approach with all organisations involved with a family. A number of 'enablers' are required for effective multi-professional collaboration. In this study 'enablers' were the development of a good relationship between the researcher and PHCT members and acute care professionals, the development of a joint care document between local health and SSDs, a LEA medication in schools policy and the high profile presence of voluntary organisation carers.

5.7 Summary

Functional ability, caring intervention and global need scores were derived for intervention and control groups. Children in the control group demonstrated less functional dependence and consequently obtained lower caring intervention scores than those in the intervention group. All families in the intervention group expressed a need for additional help at Time 1(baseline at recruitment), although the significant reduction demonstrated in global need scores between Time 1 and Time 3 may have been due to differences brought about by sample attrition. Control group families expressed less need for additional help and no significant differences between control and intervention group Time 3 global need scores were demonstrated. Matched pairs comparison of mean global need scores of the intervention group obtained at Time 1 and Time 3 was very highly significant and suggests that differences seen in the level of need were actual changes and not just due to sample attrition. Nevertheless, analysis of frequency of expressed need at Time 2 and Time 3 showed a Constancy of unmet need for one third to two fifths of families.

Both control and intervention group families expressed most need for additional help in the informational need domain with more than three quarters of families reporting a need for information about their child's illness, prognosis or about services available to assist them in their caring role.

Matched pairs analysis of the mean need domain scores showed significant reduction in the informational, practical and social domains between Time 1 and Time 3.

Children requiring intensive medical resources (DG1) demonstrated least functional dependence regarding activities of daily living, while the highest functional ability scores were achieved by children with profound disabilities (DG4). Their dependence on others was confirmed with their caring intervention scores which were twice as high as those of the other disorder groups. Mean global need scores for this group were also twice those of scores achieved by the other three groups. Significant differences were demonstrated in the disorder groups comprising the intervention group in the levels of functional ability and caring intervention scores. There was no difference noted between the disorder groups in their level of expressed need (global need scores). Matched pairs analysis of mean global need scores among the disorder groups showed significant differences for children with progressive degenerative disorders (DG2) and those with organ failure (DG3). Comparison of mean need domain scores showed significant differences for children with progressive degenerative disorders (DG2) in the informational and practical need domains and children with organ failure (DG3) in the informational need domain.

Nurse-led interventions were initiated on three levels: family, specific projects and strategic planning and policy development. Key aspects of the CCN role with families included:

- Expert knowledge
- Knowing own boundaries
- Enabling
- Empowering
- Counselling
- Effective interpersonal skills
- Listening
- Empathy
- Teaching
- Key working
- Co-ordinating
- Effective inter-professional skills
- Networking
- Liaising
- Communicating

Key aspects of the CCN role in multi-professional working included:

- Communicating
- Effective leadership skills
- Negotiating
- Collaborating
- Knowledge of policy and procedures
- Spanning professional and organisational boundaries
- Liaising
- Effective delegation of health care interventions to non-health professionals
- Recruitment and management of staff
- Effective clinical supervision
- Understanding of resource implications
- Presentation skills
- Effective dissemination of research findings

Four key aspects fundamental to the CCN role were considered as 'enablers' to effective service delivery:

- A family-centred approach which focuses on the well being of all family members not just the sick or disabled child.
- A partnership approach, working alongside families to enable them to maintain or regain control of their daily lives.
- A problem-solving approach to care is fundamental to a partnership approach where the CCN works with families to find solutions to problems experienced on a daily basis and moves away from task orientated or disease specific care.
- A collaborative working approach which spans organisational boundaries.

Essential elements of an effective CCN service extrapolated from the professional skills identified are:

- Teamwork
- Partnership
- Collaboration
- Clinical supervision
- Technical skills
- Training and education
- Evidence-based practice

Professional constraints to effective service delivery are likely to be:

- Practice based in tradition rather than driven by the needs of the population
- Lack of professional skills outlined above
- Lack of understanding of community issues
- Child-centred approach
- Disease orientated approach
- Task orientated approach
- Lack of up to date technical expertise
- Working in isolation
- Lack of recognition of joint responsibility by statutory services

Organisational constraints to effective service delivery are likely to be:

- Lack of 'enablers' outlined above
- Un-collaborative and uncoordinated approach with other organisations
- Under-resourcing
- Perceived unimportance of evidence based practice
- Poor managerial support
- Lack of clinical supervision

Chapter 6 The Continuing Care Needs Of Families – A Micro Level Of Qualitative Analysis

6.1 Introduction to qualitative analysis

Analysis of qualitative data had several aims:

- To demonstrate the complexities of the continuing care needs of families
- To enhance understanding of the needs and wishes of families
- To reveal ways to assist professionals (CCNs) with their caring role
- To offer insight into ways to anticipate the needs of families to prevent unmet need from arising and limit the effects on families when constancy of need is experienced.

Quantitative analysis of expressed need data (chapter 5.4) revealed differences in the level of functional ability, in the extent of caring interventions and in the level of expressed need between the four disorder groups. These findings did not illuminate how or why the disorder groups differed. Therefore, to enhance understanding of the needs of families of children with LTIs qualitative analysis of the interview transcripts was essential.

Huge amounts of qualitative data were generated. The data set for the intervention group comprised 69 transcribed interviews, (poor quality recording prevented transcription of four of the 73 interviews) which consisted of 46,275 lines of text (approximately 555,300 words). The data set for the control group comprised 10 transcribed interviews (three of the 13 interview recordings were inaudible). Intervention and control group transcriptions were coded separately but as themes derived from the data were intended to represent disorder groups as a whole rather than portray a frequency distribution among families, data from both groups were merged. The following micro level of analysis of expressed need data is presented by need domain and disorder group and supporting analysis can be found in Appendices 5 - 22. This level of analysis most closely reflected the views of families.

6.2 Educational need domain

6.2.1 Children requiring intensive medical resources (DG1)

At recruitment none of the children in this group had a statement of special educational need in place. All were in mainstream schooling except one child who was below school age. Families of children requiring intensive medical resources expressed needs in the following four areas:

1) For improved communication processes across the service interfaces:

> "...they don't seem to be interested the teachers, if somebody spoke to them and explained...they (health professional) should sit down and explain it to them". DG1 F4 T1

> "What I think would be very beneficial would be for school to be more clued up about things". DG1 F3 T1

2) Some families perceived the level and quality of communication between them and their child's school to be poor and, therefore, required help:

> "I've put her name down at (school), but I haven't heard from them so I don't know, I'm just waiting to find out". DG1 F8 T2

> "(Child) has specific learning difficulties. But they (school staff) are not being too precise as to what these specific difficulties are, I'm finding it quite hard to get any information on what the problem is". DG1 F7 T2

3) Training for school staff so that families perceived them as competent to undertake practical health care interventions should the need arise:

> " A link between hospital and school would be handy, especially with this adrenaline (epinephrine) business now. I feel that that's too much out of my league". DG1 F1 T1

> "I feel that the teachers and the helpers at the school really need a lot more training and education too". DG1 F3 T1

4) Families wanted someone to act as a link between the various sectors within the health services and the school establishment:

"That's me, isn't it, I'm the link between hospital and school, I don't think it is very satisfactory as me, it is better being you (researcher in intervention role) or (school nurse). I feel it gets me very upset". DG1 F7 T2

6.2.2 Children with progressive degenerative disorders (DG2)

At recruitment a third of children with progressive degenerative disorders had a statement of special educational need in place, the majority (n=5) attended mainstream schools, one child attended a special school and three children were aged below five years. A Constancy of need was demonstrated in this disorder group with issues concerning collaboration between therapy and education services; the need for advice and help with facilitating adaptations to the school environment and practical help from therapists. Three particular areas of expressed need were:

1) Practical help and advice with making suitable adaptations to a mainstream school environment and with ensuring that these adaptations were carried out:

"I'm needing a lot more at the moment (liaising with school about adaptations), to get her started and then once she's there and things are done it will be OK". DG2 F4 T1

2) A Constancy of need was illuminated for this family with this situation:

"They have half done the changing surface in the loo which is brilliant. But they haven't after (child) being there for nine months they haven't got a surface on it, ... The trouble is it is up to the school to pay. The physio came in yesterday to see her and said she would have a word to try and get it sorted out, so hopefully it will be sorted by the time she goes back in September". DG2 F4 T3

3) Concerns about their child's progress at school. Families wanted the school to pay attention to the acquisition of both academic and social skills:

"I'm not criticising his school really because they've done marvellous with him, but his reading and writing's still poorly and he's getting that much older and that's what worries me". DG2 F5 T1

"There is some apparatus she can't use, they've tried to adapt it, ... but it needs two people really. ..... It's easier when (physiotherapist) has been in and then there is the two of them, but then they've got to control the other 24 in the class". DG2 F4 T2

6.2.3 Children with organ failure (DG3)

At recruitment two children with organ failure were of pre-school age, two attended mainstream schools while the two who attended special schools had statements of special educational need in place. Families expressed a need in three areas:

1) For improved communication and information giving processes between school and family and across service interfaces:

"They're (teachers) just taking educated guesses and not having all the information they need and that seems unfair to us. And we don't know how to voice that without seeming to be the over anxious parents". DG3 F2 T1

"Yes, they do get letters about the boys, but quite a bit late sometimes. I usually go in and tell them what is happening. That (information exchange) could definitely be a bit better". DG3 F9 T1

2) With accessing practical help in the form of speech therapy:

"She is a full year behind with her speech..... Unfortunately she should have seen the pre-school teacher sooner than she actually did because the speech therapist that she has seen didn't put the form in. So had it been followed up six months earlier she might have been statemented already. So we still don't know what is going to happen but she definitely needs some extra help". DG3 F8 T1

3) For children to be educated in a safe environment:

"I must admit we are quite please with the school really. The only problem is that there is a child who is scratching the other children. (Child) has been hurt several times, which is not really acceptable". DG3 F5 T2

6.2.4 Children with profound disability (DG4)

At recruitment to the study all five children in this group had statements of special educational need in place and attended special schools. Two of the

group had full time 1:1 learning support assistance. Families reported unmet need in four areas:

1) For practical physiotherapy help during the course of the school day:

> "She doesn't do her horse riding any more which she really did enjoy.... I have been down there asking about it, but they said they had to have a trained physio there now if (child) wants to go riding... but there isn't one available for her to go so I feel she misses out on that 'cos she really did enjoy that". DG4 F3 T1

2) Families whose child did not have a learning support assistant solely dedicated to them felt that their child should have this level of support at school:

> "At school I have now asked for an assistant for her, a full time assistant, which they've told me there is no money for, I will, I'm going to push for it. I feel that the problems we've had lately are at school". DG4 F1 T2

3) For children to be educated in a safe environment. One family took quite drastic action when they perceived their child to be in danger at school:

> "I feel OK about the school apart from the accident, her split lip. It's about the third time it has happened now, ...by the same child. I'm waiting to see what happens, I kept her off school..... the deputy director of education rang up and said he'd sort something out, I didn't mind keeping her at home but I didn't want her missing out on things she enjoys". DG4 F3 T2

4) With ensuring that their child was able to undertake activities which were enjoyed, with acceptance of and participation in social skills activities rather than focussing on academic achievement:

> " She doesn't go swimming now because there are not enough staff to take her in the pool. She used to really enjoy that. They have a superb sensory pool at (special school)". DG4 F2 T1

6.3 Emotional need domain

6.3.1 Children requiring intensive medical resources (DG1)

Within this domain families of children in this disorder group reported requiring help with seven aspects related to their emotional needs:

1) For a support group:

> "I don't know whether I would use it (hospital based support group) but I'd like it to be there if I did need to". DG1 F5 T1

2) Other families expressed a need and preference for support to be offered by community health professionals away from the hospital environment:

> "I would quite like to be able to think that I can phone up someone like you (researcher in intervention role) any time of the day or night and say look I've got this series of problems. I don't like feeling isolated and just dependent on them at the hospital". DG1 F7 T2

3) For contact with other affected families or those in a similar situation:

> "You need someone else who's going through it 'cos if you try and talk to someone (who knows nothing about the illness) it sounds silly when you're saying it". DG1 F6 T1

4) Respite from the burden of daily care was regarded as an important coping resource:

> "I know that they didn't know he (other child) would have it - it's just really hard work with two of them and I don't know how I manage sometimes". DG1 F6 T1

> "So the pressure is we keep saying no and I don't think they (child's grandparents) understand the difficulties of looking after (child) in their old farmhouse (difficulties relating to allergy problems)". DG1 F7 T1

5) Someone trustworthy to take care of their child was also needed:

> "I'm not able to get to it (counselling sessions) in the holidays because there's a problem of trusting somebody to leave (child) with and always

asking the same people. Or the problem of paying for it, you've still the problem of finding somebody you can trust". DG1 F7 T1

6) Receiving appropriate and timely information was a key aspect of support for families who expressed this need to help them deal with their situation:

"I have to drag it (information) out of them and I have to keep asking questions, I actually went (to the hospital) this week and they said nothing about his condition or progress". DG1 F5 T1

7) Despite the intensive nature of the treatments received by children in this disorder group, families expressed a need to try and keep the illness low key and maintain some semblance of normality in their lives:

"He needs to get on with it (condition) and he needs to keep it as low key as possible. Maybe not to meet so many people (health professionals), but just keep seeing one Dr (hospital consultant). I think he (child) just felt that there were so many people..... to him when he has an attack, he has an attack and he gets on and sorts it out, so why when he is well is he tromping around (the hospital) sitting for hours in hot, stuffy waiting rooms". DG1 F1 T2

6.3.2 Children with progressive degenerative disorders (DG2)

Interestingly, families in the intervention group caring for children in this disorder group did not express a need for additional help within the emotional need domain at Time 1. However, during the subsequent two interviews a variety of needs were expressed particularly with coping with their future situation:

1) In particular, with developing and maintaining an informal support network, although this was not always an easy process:

"We have got on the priority list for this year (to attend disorder conference) because we really want to go and meet some other parents and we missed out last year. It is all done a bit unfairly really, but they get accommodation at (hotel) and they fill it up, and then you have to go to another one. We get cheap rates, but you have to pay extra as a daily delegate and that bumps the cost up by another half. Plus if you are travelling with turbos and things and the hassle". DG2 F4 T2

2) Others expressed a need for a more personal and individual level of contact with parents in a similar situation:

> "I would like to have contact with mothers just like me and they could say well so and so does so and so, and just pass advice on from one person to another and see what they think and what you think". DG2 F1 T2

3) Families expressed a need for assistance with members of the family such as healthy siblings, in particular with needing strategies to help them to understand the situation:

> "I would still like somebody to say to me how to break it to other children..... I would like a fairy Godmother. Because that is about the only help you're going to get, there is no concrete help, so I would like a lot of help, I would like a nice fairy godmother to come down and say this is what you do or even I'll do it for you. She's (sibling) got as far as he's going to be in a wheelchair, how do you tell her he is going to die? And this is going to be something that these people (health and social services professionals) who keep coming in and out let slip in front of her". DG2 F3 T2

4) In addition, a need for coping strategies to help families come to terms with their child's disorder and thus deal more effectively with the future was also expressed:

> "Well I suppose I do have a need (with coming to terms with the disorder) but I can't cope with it. I'm an ostrich person. There's nothing wrong with my boy and there won't be. I can take each day as it comes, it's a lot easier than having someone laying it out in front of me". DG2 F3 T3

6.3.3 Children with organ failure (DG3)

Families within this group expressed a need for additional help with a variety of aspects within the emotional need domain pertaining to managing daily life; supporting the extended family and coping with what the future holds. A Constancy of need was identified with the need for coping strategies to deal with the future hold situation, with impending life-threatening surgery and for

coping resources such as the exchange of information in a support network and from contact with parents in a similar situation:

1) Some families expressed a preference for a support network with access to professionals while others preferred a more informal approach:

> "We really just have to manage don't we? I certainly think someone to talk to would be great. Somebody probably within the professional area who has some medical background rather than just a good friend who you can have a good moan with". DG3 F6 T1

> "I would like to have somebody to talk to but it would have to be somebody more advanced than me (with a child further on in the illness trajectory)". DG3 F4 T3

2) The provision or acquisition of information was regarded as a principal coping resource for some families:

> "No I would say we're not getting any help with that either (information on how to access informal support). It's just every now and then. I don't normally get down about everything but last week..... it would have been good to talk to someone who knew what I was going through. ..... although we belong to the (specific disorder) support group, they only give out so much information, it would be nice to have contact with a family with a (disorder) child to talk about the problems". DG3 F1 T1

> "I mean most of the things we can talk about. It's purely that bit (about child dying) where there's a little barrier that perhaps we do need some more information (about what is likely to happen) to explore it a bit more". DG3 F5 T1

3) Others expressed a need for help with dealing with impending life-threatening surgery:

> "I've been dreadful, you know. It's been too much. I suppose I find it harder than (husband) because I am with her all day. I think it's because of what happened last October, with her arresting, I just keep wondering whether it is going to happen again this time (after surgery). And things might not work out so well". DG3 F1 T2

4) This situation is just one example of the Constancy of need experienced by families:

"Yes, we do need some help with that (coping with surgery). Ideally we don't want her to go through it all again, but on the other hand she has got to, there is no choice". DG3 F1 T3

5) A need was also expressed for help with informing healthy siblings about the terminal nature of a child's disorder:

"The hospice have just had a piece in the local paper..... basically it is just a back view of (child). But the headline was something about dying, and (sibling) said, (child) is not dying, and so I thought we are going to have to,..... so I want some advice about (pause) (child dying). I have read books on it but it is just finding the right words isn't it? (Younger sibling) isn't at that stage and if I tell one I have got to tell the other, because I can't put the onus on him to keep a secret, you know". DG3 F5 T2

6) Generally, families appeared reluctant to admit to experiencing marital stress, although evidence of this was implicit:

"Just when you need that extra bit of support (from husband) it's bang, gone. Coping with four children is stressful to start with isn't it, and then you have one like (child) come on the scene". DG3 F6 T2

6.3.4 Children with profound disability (DG4)

Families caring for seriously disabled children expressed a need for six particular issues within the emotional need domain, although the principal theme reflected their need for help with managing their daily lives:

1) The need for more time in the day was evident:

"He (sibling) won't go to bed at the moment. And he's quite behind with his reading they said at school, and he needs a lot of help with that. But then it's getting time to sit down with him". DG 4 F3 T1

"Our 10 year old does a lot of things and we're constantly rushing around with her as well, trying to cook the tea, quickly getting the food into (child) before she has a fit, you have got to learn to pace yourself. Any mum I think, would probably say that. But with the extra bits and pieces that you have to deal with, with having a disabled child. I would like more help at home and that's a real big issue". DG4 F1 T2

2) Some relief from the 24 hour responsibility of caring was also needed as a way for all family members to cope with the situation, in particular the need to support healthy siblings:

> "I think it's just respite care really where we need help, to get away, or so (sibling) can get away from the situation as well because it is an abnormal situation for (sibling) to have to be in. She needs to try and have some normality in her life". DG4 F4 T1

> "They're (two siblings) alright, I wish they didn't have to miss out on things". DG4 F3 T2

3) Families also revealed the need for contact with other families with similar experiences or problems:

> "I don't know anyone who has the same problems really, I think if she had the same problems as other children it would be beneficial to meet them". DG4 F4 T2

4) A need for help with developing strategies for dealing with school professionals was voiced by families:

> "I told them (school staff) that she was going to have an operation and that she was going to be very poorly, I feel I'm not getting any support from the school at all, any back-up, in fact I'm having to back them up and I find that emotionally quite wearing". DG4 F1 T2

5) In addition, families also wanted regular discussions with helpful health professionals as a way of coping with likely future events:

> "It's a sensitive issue and he (hospital consultant) is on one side and you're on the other and he feels he can't help you at all, even by giving a prognosis and yet really it's his job to give a prognosis. So the tension is impossible and it just doesn't work". DG4 F2 T2

6.4 Financial need domain

6.4.1 Children requiring intensive medical resources (DG1)

No expressed needs were coded for within this domain for the intervention group at recruitment. However, in subsequent interviews families expressed a need with three issues relating to their financial situation:

1) Worries about their housing situation were evident, and for one family the child's illness necessitated the father to organise an alternative work pattern which considerably reduce the family income:

> "I have applied for housing benefit and council tax rebate because my husband, with her being ill he's only contracting so he doesn't get paid sick pay or anything, so if he has to have a day off (with child) he doesn't get paid for it. We got a bit behind (with the rent) over Christmas not paying it because he wasn't working because she was ill ..... so I'm trying to pay a little bit off each week extra". DG1 F8 T2

2) Employment difficulties were faced by both fathers and mothers:

> "It would be really nice to go back to work. But I think no, I've got to wait until the treatment finishes, because we have to go up there (hospital) every Tuesday". DG1 F2 T3

3) Half of the families in this group received DLA although none were in receipt of the mobility component. Accessing these benefits was problematic:

> "Yes, we need to reapply for our DLA. But that's easier said than done isn't it? Have you seen the forms? Horrendous aren't they? Three books of it, I keep putting it off". DG1 F6 T3

6.4.2 Children with progressive degenerative disorders (DG2)

A number of financial implications were identified by families of children in this disorder group. Needs were expressed concerning their present and future housing situation and relating to employment difficulties. A constancy of need was revealed with housing issues regarding a need for adaptations to be made to their accommodation. A number of themes were identified:

1) Families expressed a need for financial help with making a variety of structural adaptations to their homes both present and in the future:

> "At some stage we need to look at it (making adaptations to accommodation) before the need arises because I think if we wait until the need arises then clearly it is too late". DG2 F9 T1

> "We need an extension of the back, self contained with his own bathroom and wider doors access. The Council don't have that amount of family homes adapted for special needs. They sort of adapt them as they go along. So I don't know what I'm going to do". DG2 F3 T1

> "We talked about needing an extension, but we mentioned (to social services) we might move in a couple of years (husband's job), so they've just said no, so they've given us a chemical toilet, which is a bit better than having a potty around I suppose, but it's a bit much having to empty it (mother carries it upstairs to empty it down the toilet), but I suppose it only works out that I'm emptying it every couple of weeks". DG2 F4 T3

2) The need for advice regarding employment and pension issues was a cause for concern and the following example illuminates the difficulties and dilemmas faced by families who know that their child is going to die before reaching adulthood:

> "Our dilemma is whether (father) should go for a full time post and make life slightly more difficult at home with (child) later on, or be at home and do odd jobs and be the main carer so we don't have to pay so much child care as we are now, but have no pension. Eventually when (child) goes (father) is going to be of an age where it's going to be difficult to get back into full time employment. ..... It's just so difficult when someone dies, I mean nobody knows that so they just carry on as normal. But when you know, you have to plan for it (child's death), you don't know whether you're doing the right thing for her or the right thing for you". DG2 F9 T1

3) In addition, mothers wanted to obtain some part-time employment during the school day:

> "The money would be nice (from going out to work), I would like to do something different, but then I always feel tied, tied between school hours, because I don't want anyone else to look after her. If she is like

this (poorly) and she is off school (sick), I can't then go to work". DG2 F4 T2

4) One mother expressed the need for remuneration for being her child's lunchtime supervisor at school which further highlights how mothers can be unfairly taken advantage of:

"It is a bit of a chore keeping her coming home (for dinner) and I knew she would enjoy it (school dinners) when she was doing it, so the head (teacher) hadn't sorted anything out, so I said, if I come can she stay and he said yes. ..... It is a bind, because I have to pack up at about 11.15 a.m. and have my lunch ..... I'm doing it because I enjoy it. Sticking her in her Turbo to go outside if she wants to. They advertised it (lunchtime assistant job) the Wednesday after they started back..... I said if nobody answers can I apply 'cos I'm doing it anyway and I would rather get paid for it". DG2 F4 T2

5) Families expressed a need with other additional costs particularly related to the purchase of aids to daily living:

"We really could do with some help with some sort of specialist bathroom because (child) will soon need to be bathed, washed and looked after on the ground floor". DG2 F9 T1

"We could desperately do with another toilet, it's finding the money though and where to put it. (Child) is on the toilet for hours, and I have irritable bowel syndrome which presumably is from the stress, so I can be on the loo for hours too!!. It is awful if (child) and me are bad between us. It is absolutely horrendous, hopefully we will be able to get another one eventually". DG2 F11 T1

6.4.3 Children with organ failure (DG3)

Families in this group expressed a need for financial assistance with housing, aids and equipment issues. A Constancy of need was revealed with present housing issues and the need for adaptations to the family home:

1) The need for present and future adaptations to homes was identified:

"We're seeing social services about that (downstairs accommodation) at the moment, 'cos we're trying to get an extension built because he needs this oxygen tent and there's no way I can have him in with the other boys with that (child shares a bedroom with two siblings)". DG3 F3 T1

"(Sibling) is now at secondary school, and he wants to go to bed and lay and read, but that causes problems if (child) hasn't gone to sleep (they share a bedroom), then (sibling) has to stay up a bit later, so yeah they need separate bedrooms". DG3 F6 T2

2) This quotation illustrated the Constancy of need for appropriate housing:

"It makes it (the noise from oxygen concentrator) even worse having the stair lift 'cos it reverberates even more, it's really noisy. It's really made it even louder and it was bad enough before. At night, with not being able to hear (child) I can't sleep, ... You worry yourself silly. We need this move (housing association transfer) sooner rather than later now. .....I'm moving with (child) 'cos so I've got room for his machines and six boxes of nappies every two months (incontinence service delivers large amounts of aids infrequently)". DG3 F3 T3

3) Families expressed a need for financial help with purchasing daily living aids and medical equipment:

"We're trying to get a special bed for him like a cot bed because he keeps falling out, and we're after an intercom system so we can hear him as well". DG3 F3 T1

4) One mother revealed a reluctance to gain employment for fear that she would have less income than she received with benefits:

"It would have to be something that was really worth my while because otherwise we would lose the benefits, to be honest I don't think I'm qualified for anything to cover that". DG3 F9 T1

6.4.4 Children with profound disability (DG4)

Families of children in this disorder group expressed a range of needs: housing issues, employment difficulties, daily living aids and transportation.

1) Need was identified for both present and future structural adaptations to the family home or for the purchase of appropriate one storey accommodation. Although grants were available families invariably had to contribute a substantial amount of money themselves:

"We really need to sell this house and buy a bungalow but I don't think we can possibly afford it, ... unless we went out in the wilds somewhere

because it would be too poky to be of any practical use for a handicapped child. You need a fairly spacious bungalow and we'd have less space than we've got here I think if we bought a bungalow for £90,000 in (village) or here abouts. So we seem to be stuck at the moment". DG4 F2 T2

"They've approved her extension,... Mind you, now they're going to ask us for some money and that will be a laugh won't it?". DG4 F1 T2

2) The need for aids to daily living was also reported:

"We need her bedroom twice the size it is and a bathroom twice the size, that's all really, we manage but it is just not big enough now she is getting bigger. I need a plinth in the bathroom to dress her on". DG4 F3 T2

3) Transport related problems were also revealed and families reported requiring large sums of money to purchase an appropriate vehicle which would accommodate their disabled child, aids and equipment and the rest of the family:

"The actual deposit for the Renault Espace which is what we really need is £4,400, which we can apply for a grant for, but if we don't get it she (social worker) will apply to different charities". DG4 F3 T2

4) Families experienced financial hardship as mothers found it impossible to seek employment because of difficulties related to caring for a disabled child:

"I would really like to be able to do it (go out to work), but I just can't. Unless you're loaded, so you can afford to have a nanny come in, you can't do it". DG4 F1 T2

6.5 Informational need domain

6.5.1 Children requiring intensive medical resources (DG1)

The informational needs of families in this group related to the child's disorder, progress and treatments; about the availability of services in the area and concerning the need for improved communication and information

exchange between professionals from different agencies. A number of themes were evident:

1) Families expressed a need for information because they wanted to participate in their child's management but did not know what to ask:

> "(Child) has been having them (drug) for six years and I've only just been told (of potential adverse reaction with other drugs), you don't actually know if you need more information 'til you're actually given it". DG1 F6 T1

2) Some families were lacking very basic information about their child's treatment and the effects of treatment and would have liked to be more informed:

> "I know how to get information, but there's only one thing I don't know what the tablets are for". DG1 F4 T1

> "I seem to ask but they haven't got the results there to hand to tell me, I just want to know a bit more about that (investigation), they tell me about her treatment, what she's going to have done, but they are not telling me what effect it's having". DG1 F8 T2

3) Others expressed the desire to keep up to date with new treatments:

> "I would think that although we have had a lot of information there is something about keeping abreast of things. I'm rather worried that we might slip back and not have the most up to date information". DG1 F3 T1

4) Some families did not seem to have a mechanism in place which allowed for their child to be regularly reviewed by secondary health care professionals and which offered them the opportunity to ask questions:

> "(Two hospital consultants) are not around so we never get the chance to ask questions. What would be a good idea would be to have a parents evening every six months or so like at school so that we could ask questions if we had any. It would also be better then because (child) wouldn't be around". DG1 F2 T2

> "It would be useful to have six monthly or yearly reviews to see where he's at with everything not just with one bit or another. He was completely discharged from the system (tertiary centre) whereas what

we wanted was to say okay we can just see the GP and maybe have an appointment (with the tertiary hospital) every six months". DG1 F3 T1

5) Families were willing to find out information for themselves but reported difficulties with this process. Needs were expressed concerning information about services available in the area:

"I think information of what services are available to children and families could be clearer, it could be brought together so it was easier to access, ... you go from one person to another and then find you still haven't found out what you wanted to know anyway". DG1 F7 T2

6.5.2 Children with progressive degenerative disorders (DG2)

Families in this group expressed a need for information about their child's disorder and about services available to help them. The poor level of exchange of information between statutory services was also cause for concern and families expressed the need for additional help:

1) Families went to great lengths to confirm their child's diagnosis despite the rarity of some disorders. A diagnostic label was perceived as important as it meant that they were more likely to be able to meet other families with similar children:

"If (child) was only ill two or three times a year, and there was no long term effect from it, I would say OK forget it..... I will live with it. But ..... it (set of symptoms) was happening so regularly and for so long (five years) and (she was) missing so much time off school and we are still not sure about her liver function and why she spikes such a high temperature..... At (tertiary centre - recent second opinion referral), they said come back in three months time after I have spoken to some liver bods (experts) and things". DG2 F2 T2

2) Families in this group also expressed the need to keep up to date with new treatments:

"I would like to know if there is anything (new treatments) coming out that is not here yet". DG2 F1 T1

3) The lack of proper channels of information exchange between tertiary and primary health services was a source of anxiety for parents:

> "It (treatment plan) should be put down in writing (by tertiary centre) so there is no mistake about it and then when the GP rings me up and says: well I'm not happy about (prescribing) this, I can say well this is what we have agreed with (tertiary centre)". DG2 F7 T1

4) Other families expressed difficulties with communication processes between services and themselves:

> "I get fed up with waiting for a result, I ring them and then it will move on from there whether they think it's worth doing anything else or not, but I mean I haven't got an outpatient appointment for her or anything because they don't bother giving them to me". DG2 F2 T1

5) No families in this group had a designated professional acting in the role of key worker. However, families expressed the need for such a person:

> "There has got to be a static person who really knows the job, knows everybody else who you can meet. One person who tells you that yes, I'm here for you, I will be at the end of the phone, if there are any problems I will sort it out and get somebody who knows the job to get back to you". DG2 F3 T1

6) The paucity of information about available services in the area was also evident:

> "Well I still think that's (availability of information) fairly poor. I don't think, unless you go out and really look very hard and follow it up hard yourself, nobody's going to tell you. For example, we need to find out about special needs schools ..... because we have to start thinking about that soon". DG2 F7 T2

> "What would be nice would be a simple list of people, who they are, what they could help with and how they could be contacted..... in layman's terms and know their telephone number". DG2 F3 T1

7) Others wanted specific information about social activities:

> "It would be good to have a really good network you can ring up and say where's a good place to take (child) you know, or to get feedback from

other parents ..... like leisure activities or how to entertain a child who can't walk properly". DG2 F3 T1

6.5.3 Children with organ failure (DG3)

Families caring for children in this disorder group also expressed a need for information about the child's disorder, and available services in the area; about specialist tertiary services and concerning the exchange of information between the different statutory organisations. A Constancy of need was revealed regarding the need for information about the disorder:

1) This was a source of anxiety:

> "We'd like generally more information. You get told one thing and you go back they tell you a different thing that contradicts it and..... you're not sure which one is right and .....you really want to have it set". DG3 F4 T1

> "If they (tertiary centre) say they can't do anything we will be very disappointed. I mean one half of me is desperate to get him there because I want to know what it is all about, but the mother inside me says not again I've had enough of it. Having it (battery of investigations) done at (tertiary centre) it will be a similar sort of thing and (child) really hates it.....I'm apprehensive to say the least. I don't even know if they deal with children over there, do they have a children's ward?" DG3 F6 T2

2) The need for information about treatments for the control of symptoms was expressed:

> "It's just that she (tertiary centre consultant) has just said that he might do better with the oxygen and everything, and we've got to get the ball rolling, but we don't know anything about it". DG3 F3 T2

3) A need was also revealed for regular discussion with health professionals:

> "I don't know if it's really necessary to see someone every three months. But it would be nice..... to know that you can go to somebody if you need to". DG3 F5 T1

> "It would be good now (to discuss child's progress regularly) because there are always little things you notice that do worry you". DG3 F3 T1

"She (health visitor) doesn't tell me anything. If there is anything I should know, I don't, I haven't been told". DG3 F1 T2

4) Specific information about sources of financial assistance was also an area where families wanted help:

"We haven't had any help, (with extension). We didn't know what was available (sources of financial assistance). To be honest we really need some help with it. It's something we've talked about doing for a long time and it's been pushed forward quicker (because of child's condition)". DG3 F6 T1

5) Families also expressed the need for information from the statutory services other than health:

"(Child) has been referred to the pre-school people now. Hopefully we should know something fairly soon..... they'll monitor her at home and say whether they think she needs any extra help at school or not". DG3 F1 T2

6.5.4 Children with profound disability (DG4)

Families caring for children with serious disabilities also expressed the need for additional information about aspects of the disability and about services which were available to help them:

1) Families felt that they wanted more information about the disability and prognosis to understand the disability and not "just manage". A Constancy of need was revealed in which one family seemed resigned to not having all the information they desired:

"Certain things about it, like (an aspect of the disability) I've never been able to understand that". DG4 F3 T1

"Yeah, well I suppose we manage (with information)". DG4 F3 T3

2) Others wanted regular contact with health professionals not necessarily to discuss their child's progress but more for a listening ear from someone who understood and could empathise with their situation:

"It would be nice to have someone to talk to. It is difficult sometimes if you don't have anyone to talk to, it tends to get bottled up and you don't have a release do you, 'cos you can't go next door, and she can say oh don't worry mine does that 'cos obviously her children don't do that (are not severely disabled)". DG4 F1 T1

3) Families expressed a need for information about services which could assist them in their caring role. In addition, a desire for specialist services in the area was expressed to avoid the need for travelling some distance to tertiary centres:

"A babysitting service, that's what I need to find out about". DG4 F3 T1

"They don't have anyone locally (who specialises in the disorder). That's just it. They ought to have a (disorder) consultant, but then it's money again isn't it?" DG4 F1 T2

4) The lack of easy access to services also caused additional pressure for families:

"I've been trying to get hold of Dr (GP) 'cos he's got to sign them (motability forms) and state what's wrong with her before they will terminate the contract on our present car. I'm sure he'll do it but it's just a case of getting to see him". DG4 F3 T2

6.6 Practical need domain

6.6.1 Children requiring intensive medical resources (DG1)

The sole higher range of abstraction theme revealed from the expressed need data for this disorder group in this domain concerned the need for assistance with medical equipment:

1) In particular, a need was demonstrated for servicing and repairing equipment which families had purchased themselves:

"It would be a lot easier if we could take it (nebuliser) somewhere and get it serviced here. Also I don't like to be without it. One thing when we had the one (loaned) from the hospital they took it and serviced it and reconditioned it". DG1 F3 T1

"We could do with a new mouthpiece and mask at the moment and a new lead really (for the nebuliser), but we have to get in touch with Medicaid but we always purchase those". DG1 F1 T1

6.6.2 Children with progressive degenerative disorders (DG2)

In contrast to the previous disorder group, families of children with progressive degenerative disorders expressed a need for numerous issues pertaining to medical equipment; transportation and intersectorial working:
1) A need was revealed for equipment to administer treatments and to assist families in performing therapies. Families expressed a need for the opportunity to try equipment before purchasing to see if it suited their child's needs as equipment was expensive:

"After the trouble we had when we were (abroad) I sort of felt it would be handy to have a portable nebuliser. You really need one as stand-by because when you need it you don't have it...- so it's just something you need to have even if you don't need to use it all of the time". DG2 F7 T1

"No I haven't got a tipping frame unfortunately, I've got a very old fashioned thing out there and I'm after a new one now 'cos I need something higher now that he's bigger". DG2 F5 T1

"We do need ..... to be able to try out different equipment. This equipment is expensive, you don't want to order it and then find that you've bought the wrong thing. There is very little help there". DG2 F7 T2

"She's got a wedge and a roll (at school), but the roll is much too soft, so we've got to try and get another one of those". DG2 F4 T2

2) In addition, families expressed the need for vehicles with more space to accommodate their child's mobility aids and equipment:

"Well the problem is with the Turbo (electric wheelchair) - I can't get it in my car. We need a bigger car and we can't afford to buy one". DG2 F4 T1

3) For some families the lack of their own means of transport meant that they had to rely on public transport for access to hospital and appointments as well as getting out and about in everyday life:

> "Yes we have transport problems, we have difficulty to get there (hospital) all the time and I don't know how to drive. I suppose eventually I will start my driving lessons. We went to the Family Fund (for some money), it is nearly a year I have had the money for it but I don't have a chance yet,..... with looking after the both of them". DG2 F6 T2

4) Families with their own transport, however, revealed difficulties with travelling to a tertiary centre for outpatient appointments:

> "The only problem is getting down to London (tertiary centre) and back. It is difficult however you do it, whether you go by train or car, but..... I suppose it's our choice, because we think the hospital is a centre of excellence as far as (disorder) goes". DG2 F7 T2

5) Difficulties with accessing the mobility component of the DLA was revealed and families expressed the need for improved communication between services:

> "It is just under three months until she is five, and I would like to get the car as soon as possible. The garage won't process our (motability) application any further until they have got written authority that she is eligible. I just seem to be ringing them (benefits agency) every week at the moment and they don't seem to know what they are doing. I wish there was something somebody could do about that". DG2 F4 T2

6) Resource issues to resolve housing difficulties were also revealed:

> "I still would like to get the move done (to suitable one floor accommodation) and I've got (sibling) starting a new school in September,..... But I think you have to get right to the very limit before they (Council) do anything, ... You have to be homeless before they consider homing you". DG2 F3 T3

6.6.3 Children with organ failure (DG3)

Families caring for children with organ failure expressed a variety of needs within this domain. In particular, with medical equipment, aids to daily living,

issues concerned with transport and a collaborative working approach from statutory services. A Constancy of need was illuminated with medical equipment for the administration of treatments and controlling their child's symptoms and with the need for aids to assist daily living:

1) Families expressed a need for equipment to administer treatments and with mobility aids:

> "They (GP surgery) ring up and ask for it (nebuliser) back. But when (child) goes downhill he goes extremely fast and he could be absolutely fine in the morning, coughing at lunchtime and in hospital by tea-time. So we need it here". DG3 F6 T1

> "The only thing I must get sorted is this wretched buggy, it is driving us mad. They (local hospital) said they would see about having someone come out and see to it..... But I have not heard anymore, so I must contact them and see". DG3 F5 T2

2) Need for additional help with transport issues concerning emergency admission to hospital and for ease of parking was revealed:

> "If we have an emergency or the doctor says to go to the hospital, we feel that they (hospital) should be able to help out a bit more because we don't have a car". DG3 F2 T1

> "We really need one of those orange badges, just so you can sort of just like park somewhere and, you know, when you have to go to hospital it would make life a lot easier". DG3 F3 T1

3) For one family, their child's journey to school was a cause for concern:

> "It is the half an hour that is wearing (child) down, anybody who travels by bus gets tired so you can imagine how tired he is by the end of the day. He has to climb in from the front steps,..... and there's three or four steps to get up which he obviously didn't have (to climb) when the taxi took him, it's not any easier. I need to speak to (headteacher) about it". DG3 F3 T3

4) Families also expressed a need for the different services involved in their child's care to work together:

> "Someone (from social services) is supposed to be coming around on Monday to see what (difficulties of noisy medical equipment and

cramped living conditions) they can do. It's just getting beyond a joke. I've got (two siblings) asthmatic, the baby like it as well, I've got (child) how he is and everything..... and I'd really like it sorted out. No one seems to be talking to each other". DG3 F3 T3

6.6.4 Children with profound disability (DG4)

Families caring for children in this disorder group expressed needs relating to aids to daily living, particularly with the need for moving and handling and mobility aids to deal with large scale movements of their child. Transport difficulties were highlighted and intersectorial working in relation to the need for adaptations to the family home was also revealed. A Constancy of need was illuminated regarding mobility aids and adaptations to their accommodation:

1) Aids to daily living in the home were required:

> "She (occupational therapist) says we really need a lift in the house if we're not actually going to move to a different house altogether like a bungalow. She actually wrote to us a few weeks ago..... We haven't actually answered yet ..... we need lots of things but we can't afford them, except for the car which we will have to be able to afford. 'Cos we've got to get her from A to B. She's getting to a size now that we can't easily lift her in and out of cars without endangering our backs and that's even more so with (child's mother)". DG4 F2 T1

2) Difficulties with mobility and seating aids were revealed:

> " We have had so many visits related to her chair it is ridiculous, even now the tray isn't right and things like this. 10 months after we first went she's almost grown out of it now, so I'm waiting for another appointment for the seating clinic". DG4 F4 T1

3) Families expressed a need for practical and financial help with transport related concerns:

> "Well, we've got the car for mobility, but the car's just not big enough. We need something bigger. The actual moulded seat is a brilliant idea for her, it's just a real hassle because it's so big and it don't fold up, that's the problem with the car it's just not big enough for that chair and (child) and the other two (siblings)". DG4 F3 T2

"The only real worry we have now is as we've got this car which carries a wheelchair, is the wheelchair itself built strong enough to withstand those sorts of stresses of being used in the car. In particular, does she need a head rest. I've taken this up with (local hospital) and they just won't hear of her having a head rest for that reason. But I think she's in danger of a whip lash injury if I have to stop suddenly". DG4 F2 T2

6.7 Social need domain

6.7.1 Children requiring intensive medical resources (DG1)

Within this domain families in this disorder group expressed a need for respite care and help with managing daily life:

1) A difficulty in finding an appropriate babysitter able to administer medical treatments was highlighted:

"Babysitting we definitely need. Somebody sort of qualified too, to do the nebulisers, because we don't go out anymore because we used to have to cancel so often..... and people who we were going out with got fed up as well". DG1 F6 T1

"It would be nice to have some respite from time to time but it would be a luxury really. It's more often a problem in the holidays in the day time. You can tell most other parents aren't keen to have him at their houses". DG1 F7 T2

2) Respondents also expressed the need to be able to get away from home and enjoy a break with their partner:

"We're desperate to go away for a weekend - just the two of us". DG1 F6 T1

3) Families did not rate highly the need for help in their daily lives, although a need was expressed for domestic help in the home:

"I would like some help with housework, I can think of things I would much rather be doing". DG1 F7 T2

6.7.2 Children with progressive degenerative disorders (DG2)

Needs were expressed within three higher range of abstraction themes by families caring for children with progressive degenerative disorders: respite care; help with managing daily life and help with daily care and treatments. A Constancy of need was revealed by families for respite care, in particular with needing a babysitter able to deal with an emergency situation and having the opportunity to enjoy a break without their child(ren):

1) The principal factor with respite care concerned the need for a babysitter to be able to deal with an emergency medical situation:

> "It's difficult to find someone to baby sit him because they say, oh well, I don't know his problems - what do I do if something happens". DG2 F5 T1

> "I've got somebody that I can ask (to baby-sit) but really.....she would get involved but she doesn't really want to do so to a great degree. I haven't asked anyone else 'cos I tend to try not to in case that person who I ask doesn't want to in case something happens". DG2 F1 T3

2) Some families in this disorder group were already receiving respite care, however, it was not always consistent, regular or sufficient to meet their needs:

> "We need to do a couple of nights where I literally drop her off, she goes to bed and I come back and pick her up in the morning (host family respite care), to get her back into the swing of going because she's not been going regularly in the last six months ". DG2 F4 T2

3) Respondents in this group also expressed the need for some time alone with their partner:

> "Yes it would be good to have a sort of break with (child's father), but I'd probably soon miss her though!". DG2 F7 T1

> "We do sometimes need a break just for us two". DG2 F6 T1

4) The expressed needs concerned with managing daily life reflected both the need for domestic help but also help for the family while the principal

carer (mother) was resident in hospital with the child. In addition, the need for stimulation outside the domestic situation was also revealed:

> "I'd like to do more in the house than I do. I just tend to whiz round with the Hoover when she's not here". DG2 F4 T1

> "At times I need help (with the rest of the family) while I stay in hospital with her. It depends how I can organise it". DG2 F2 T1

> "I think probably I do need something outside the domestic situation..... I think sometimes it is more important to get that when you're in a situation like this". DG2 F7 T2

5) A need for assistance with performing therapies and caring interventions at home was also identified:

> "Well it would be nice occasionally to have someone else do it (perform physiotherapy) for you, you know, for a change". DG2 F5 T1

> "The only thing I feel the need for is some physio help, ...that's what's lacking. It's not only physically exhausting, it's mentally exhausting because she (child) hates it, I hate it ..... it is extremely hard to get it done effectively and it's not something you can brush aside because it has to be done. I think the trouble is at this age the whole thing is just one continuous fight, you know. You're fighting to get (drug) into her, she's getting a bit more difficult over her (drugs) now, so you need a break every now and again". DG2 F7 T2

6.7.3 Children with organ failure (DG3)

Families caring for children in this disorder group also expressed a need for respite care and help with performing daily care and treatments. A Constancy of need was revealed for day and night time nursing assistance with daily treatments and with additional respite care at home and in residential establishments:

1) A need for more frequent respite care was expressed. The following two sets of three quotations demonstrate the Constancy of need expressed by two families over the study period:

"We have this link (scheme) lady um but it's not often. It's just often enough to keep our heads above water". DG3 F6 T1

"That avenue of respite care has died a natural death at the moment. They moved house and she last had (child) for an afternoon about four or five months ago. I need someone during the day because the problem (with) nebulising three hourly (is) I get fed up with doing it. ..... it is time consuming and when you're trying to do things for the other children as well. It is one of the main reasons we go into hospital is I've had enough, I'm tired out. And I'm aware now when I get tired everybody suffers". DG3 F6 T2

"Well I don't want him out of my life, but we do need a bit more (respite) when he's not well and starting to get better, we could probably do with some respite then to get a decent sleep. In the home would probably be best, 'cos he's not the sort of child to take to somebody, it doesn't really happen often enough for him to get used to somebody. If we had a stranger in there is no way he is going to settle, so we probably need somebody like a nurse who doesn't work so is available at short notice". DG3 F6 T3

2) In this second example of Constancy of need the family expressed a need for help with care and treatment although such care was not always required from a trained nurse:

"When he is sick he's very sick and with the vomiting you can't really leave him, as soon as you turn your back he's choking, so then we do need trained (nurse) help". DG3 F5 T1

"Well on the whole we manage, it's really just the odd night, really when things just get that little bit too much and we could really use some help (respite)". DG3 F5 T2

"With experience I've found ..... he doesn't need full nursing care, although this last time he did, because I really was concerned about him but it's not always a necessity, it's just we need someone to be with him". DG3 F5 T3

6.7.4 Children with profound disability (DG4)

Respite care and help with daily life were the principal higher range of abstraction themes identified by families caring for children with disabilities. A

Constancy of need was revealed with the need for a babysitter able to deal with the complexities of the disability:

1) Families expressed a need for someone able and willing to deal with practical consequences of the disabilities such as moving and handling, feeding and suctioning. A need for any amount of respite care, large or small, was revealed:

> "My mum comes in but it would be nice to have another source 'cos you don't always like to ask. It is alright if you've got ordinary kids, you can get a young girl in to look after them but not when you've got (child)". DG4 F1 T1

> "Any percentage of respite care would be welcome. There might come a time when we can't do anything for (child) because we're too old and weak and she's too heavy so then we'll have to drop out of it altogether. I hope that (day) never comes and I hope the main way of fending that off is by getting as much respite care as possible". DG4 F2 T2

> "I need help with babysitting and someone (from a social services scheme) has been to see (child) but (two siblings) were really on form that night so I don't know whether she'll come back or not." DG4 F3 T2

2) The following quotation from the subsequent interview revealed that for the family above the social services scheme did not meet their needs:

> Respite - you mean childminding or babysitting? We're not really getting anything, no help with that, anything would be a big help". DG4 F3 T3

3) Families were reluctant to express the need for domestic help in the home:

> "I don't get any help no (with house work). It would be great to have someone to come in and put the Hoover round and just do a bit of ironing. Unless you can keep up with it,..... you're always rushing with everything. I tend to do mine at 11 o'clock at night when they're all in bed". DG4 F1 T2

> "I'm from the old school really, I feel I ought to fight for myself ... and overcome my own problems. But that's probably wrong when you've got a handicapped child on your hands and you're getting older. So I think certainly (wife) would say yes we need some domestic help at home". DG4 F2 T1

6.8 Mezzo level of analysis of expressed need

6.8.1 Core themes and the creation of Need Zones

Themes generated from the micro level of analysis of expressed need were subjected to further examination (mezzo level of analysis). Core themes common to all disorder groups emerged from higher range of abstraction themes (outlined in Appendices 5 -22). These core themes offered a recurrent and unifying image of the domain across all disorder groups and throughout the 'snap shot in time' of the one year period (three interviews). All six core themes were considered to reflect a truer picture of the needs of families than the original need domains and thus domains were superseded with the creation of Need Zones headed by the six core themes.

Table 50 Creation of the six Need Zones

Original need domain	Need Zone
Educational	Intersectorial working (multi and single sector i.e. single sector being between service providers and family)
Emotional	Coping strategies and resources
Financial	Extra help with costs of caring
Informational	Information
Practical	Equipment and resources
Social	Extra help with practical caring

Following the development and refinement of six core themes common to all groups, mezzo analysis of themes continued with some minor changes taking place to the positioning of higher and middle range of abstraction themes within the Need Zones. This ensured that they were clustered more appropriately with themes similar to them. For example, help with daily care / treatments was perceived to 'fit' better with themes within the Extra Help with Practical Caring Need Zone (ex social domain) than with themes reflecting the need for Equipment and Resources. Incidences of expressed need for information about sources of financial assistance were moved from the Need

Zone concerned with the Extra Help with Costs of Caring to the Information Need Zone. Housing issues which related to the need for information about sources of financial assistance to make adaptations to housing were moved from the extra help with costs of caring need zone to the Information Need Zone. Similarly, themes corresponding to the need for additional financial help with transport or housing issues were moved from the Need Zones for Equipment and Resources and Extra Help with Practical Caring respectively to the Extra Help with Costs of Caring Need Zone.

6.8.2 Development of Maps of Expressed Need

The generation of themes of different levels of abstraction in the six Need Zones contributed to the production of Maps of Expressed Need for the four disorder groups (figures 6-9). Evidence (6.2-6.7) and data from Appendices 5-22 are presented for each disorder group in an elliptical map, segmented to provide areas for the six Need Zones. Thus, themes in each Need Zone are depicted radiating out from the centre, becoming increasingly more specific (i.e. less abstract) with each concentric layer. The inner ellipse comprises the core themes common to all disorder groups, the middle ellipse contains themes of a higher range of abstraction, while the outer ellipse consists of middle range themes which most closely reflect the summary of expressed needs generated directly from the verbatim quotations. The production of individual Maps of Expressed Need for each disorder group illuminates the uniquenesses of the different disorder groups. Their diversity will be reflected upon in Chapter 7 where further evidence contributes to the production of models for the six Need Zones which facilitate a comparison of need between individual disorder groups.

6.8.2.1 Map of Expressed Need: Children requiring intensive medical resources (DG1) (Figure 6)

Children requiring intensive medical support had cancer, severe asthma or serious food allergy with the potential for anaphylactic shock, and their families demonstrated a range of needs within the six Need Zones. Most

striking were the needs reported within the Coping Strategies and Resources Need Zone. The micro level of analysis revealed a range of issues which pertained to the need for strategies to come to terms with the illness and helping extended family members to understand the situation. In addition, the need for practical resources to help them manage the situation such as appropriate respite care and the availability of community health professionals equipped with skills to anticipate or respond to their needs was also revealed. A need for a more informal coping resource was also demonstrated. Contact with other affected families was requested so that information and support could be exchanged thus equipping families with additional coping strategies with which to manage their situation. The need to minimalise their situation and thus maintain some normality in their daily lives was expressed by this disorder group only.

In comparison with other disorder groups the Equipment and Resources Need Zone was peculiar to this group in that only the need for servicing and repair of medical equipment was reported. Although the identification of need did not reflect a frequency distribution among families, only one family identified the need for equipment to administer treatments and monitor the child's condition. While this has been included on the Map it is perceived as unrepresentative of this group, who already owned or had on loan the necessary equipment for their child's care.

This disorder group differed from others in that at the recruitment interview none of the children had a statement of special educational need in place and all were being educated in main stream schools except for the child who was too young. Within the Intersectorial Working Need Zone the need for two key aspects of effective service delivery was expressed. Firstly, families called for a partnership method of working with school staff. For example to obtain more information about their child's needs as poor levels of communication were a cause for concern. Secondly, an area of need peculiar to this group concerned the need for training for school staff to be competent to undertake practical health care interventions should the need arise.

Expression of need for help with the financial implications of caring for a child with a LTI was peculiar to this disorder group in that no needs were expressed at the recruitment interview. Subsequent interviews provided an opportunity for families to report some needs regarding their financial situation. Most concerns pertained to difficulties with employment necessitating a different work pattern which brought about a loss of earning power. In the case of mothers the fact that they had given up employment to care for their sick child emphasised a loss of social support as well as the loss of finances. Only half of the families in this group received the DLA benefit but difficulties were reported with accessing such assistance.

Within the Extra Help with Practical Caring Need Zone families revealed a need for respite care and assistance with daily life. Difficulties with finding a babysitter able to administer medical treatments were revealed peculiar to this group as was the need for respite during school holidays. In addition, families did not rate highly their need for assistance with their daily lives although a need for some help with domestic duties was expressed. Being able to get away from the home for a break with their partner was revealed by the respondents in this and the group of children with progressive degenerative disorders (DG2).

Information is a fundamental aspect of care and management for families caring for children requiring intensive medical resources. Families expressed a need for information about their child's disorder, treatments and progress, and services available to help. Families also wanted improvements in the level of intersectorial information exchange which they perceived would improve their situation and enable them to participate in their child's care and management. As with other disorder groups information was wanted which was clear and easily accessible, although this group were willing to find out information for themselves but reported difficulties with this process.

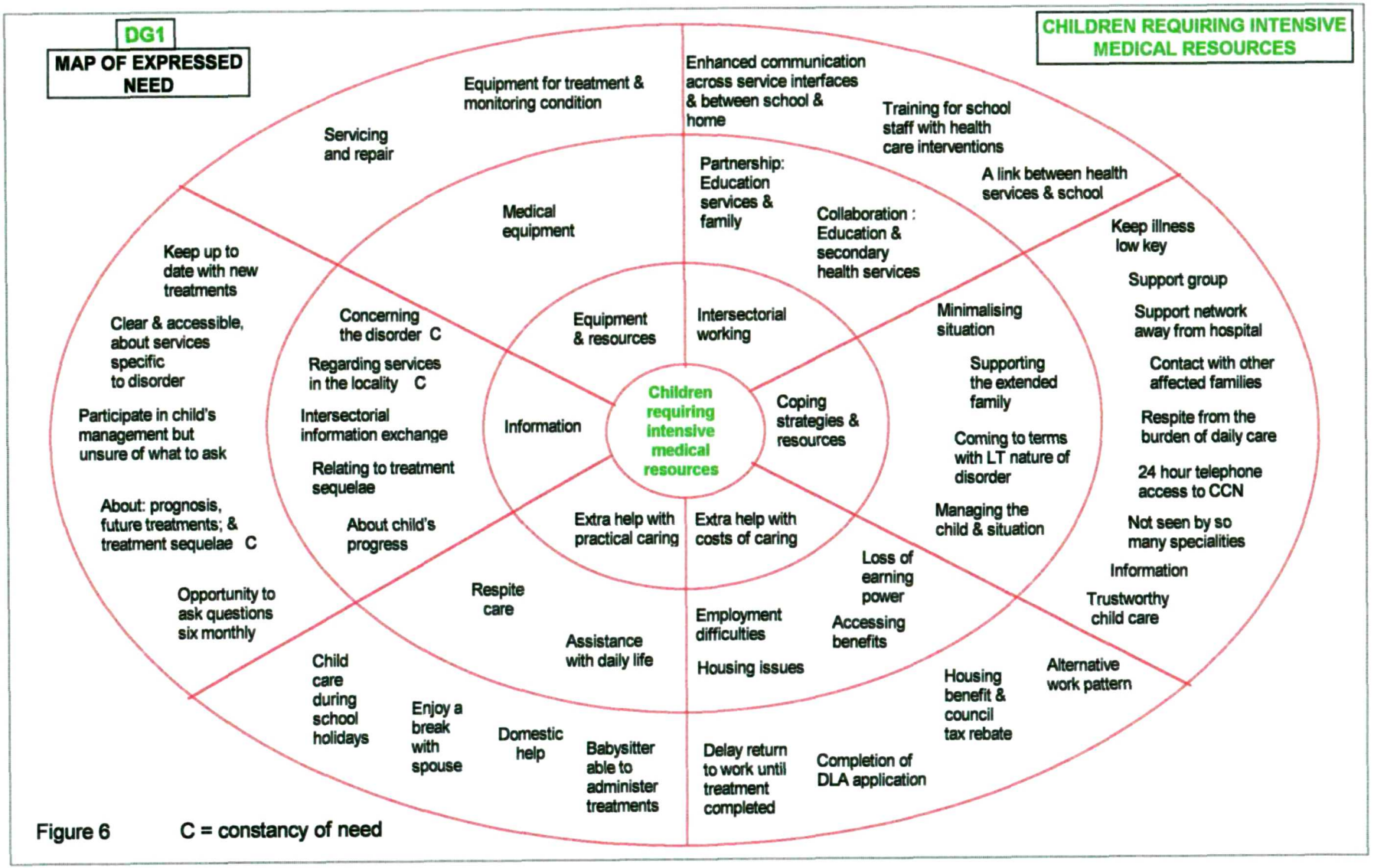


Figure 6 C = constancy of need

6.8.2.2 Map of Expressed Need: Children with progressive degenerative disorders (DG2) (Figure 7)

This disorder group comprised families caring for children with progressive degenerative disorders such as cystic fibrosis, Duchenne muscular dystrophy, spinal muscular atrophy and mucopolysacharidoses. A range of needs encompassing all the six Need Zones were expressed.

Families revealed a constancy of need with the need for a collaborative working approach between therapy and education services, the need for advice and help with facilitating adaptations to the school environment (and ensuring that these adaptations were carried out) and with practical help from therapists with school activities. Families wanted their child's school to pay attention to the acquisition of both academic and social skills as some were concerned with the lack of their child's academic progress. The extent of Constancy of need within this Need Zone was specific to this disorder group and highlights the importance of a multi-professional and intersectorial working approach.

At recruitment this disorder group did not express a need for additional help with coping strategies and resources. Needs, however, were expressed during subsequent interviews which pertained to developing and maintaining an informal support network (not always an easy process) and the need for contact on an individual basis with other affected families which would help them cope with their child and help sustain their family. Families revealed the need for strategies to manage their situation better, come to terms with the disorder and to deal with future difficulties and the eventual death of the child. In addition, the need to develop strategies to help their healthy siblings to understand the situation was also highlighted.

A number of financial implications were identified by families. Needs were expressed concerning their present and future housing situation and relating to employment difficulties. Analysis of serial data revealed a Constancy of need regarding the need for adaptations to accommodate their child.

Financial help was needed to make a variety of structural adaptations to the family home, with some families planning ahead and revealing that such assistance would be needed in the future. The problems and dilemmas of families who know that their child is going to die before reaching adulthood caused concern for families and were reflected in this group's need for advice with employment and pension issues. Difficulties of mothers in particular were revealed here with their need for employment around school hours and for remuneration for assisting their child at school due to the lack of available lunchtime support for which funding was available. The purchase of aids to daily living was also an area where families expressed a need for additional help.

The need for information about their child's disorder and to rectify the paucity of information about available health and leisure services in the area was also expressed by families caring for children with progressive degenerative disorders. The poor level of exchange of information between the various statutory services particularly the linkage between primary and tertiary services was a source of anxiety. Other concerns relating to information exchange related to the fact that families perceived that communication processes between them and professionals were poor. No families in this group had a designated professional acting in the role of key worker and families expressed a need for someone to co-ordinate services within a keyworker framework. Families of children with particularly rare disorders went to great lengths to confirm their child's diagnosis because they perceived the possession of a diagnostic label placed them in a better position to meet other families with similarly affected children. They felt that this would help them gain support from being able to share experiences. Keeping up to date with new forms of care and treatment was an area which this group felt to be important.

In contrast to the expressed needs of families caring for children requiring intensive medical resources (DG1) this disorder group expressed a need for additional assistance with numerous issues within the Equipment and Resources Need Zone. In particular a need was revealed for equipment to

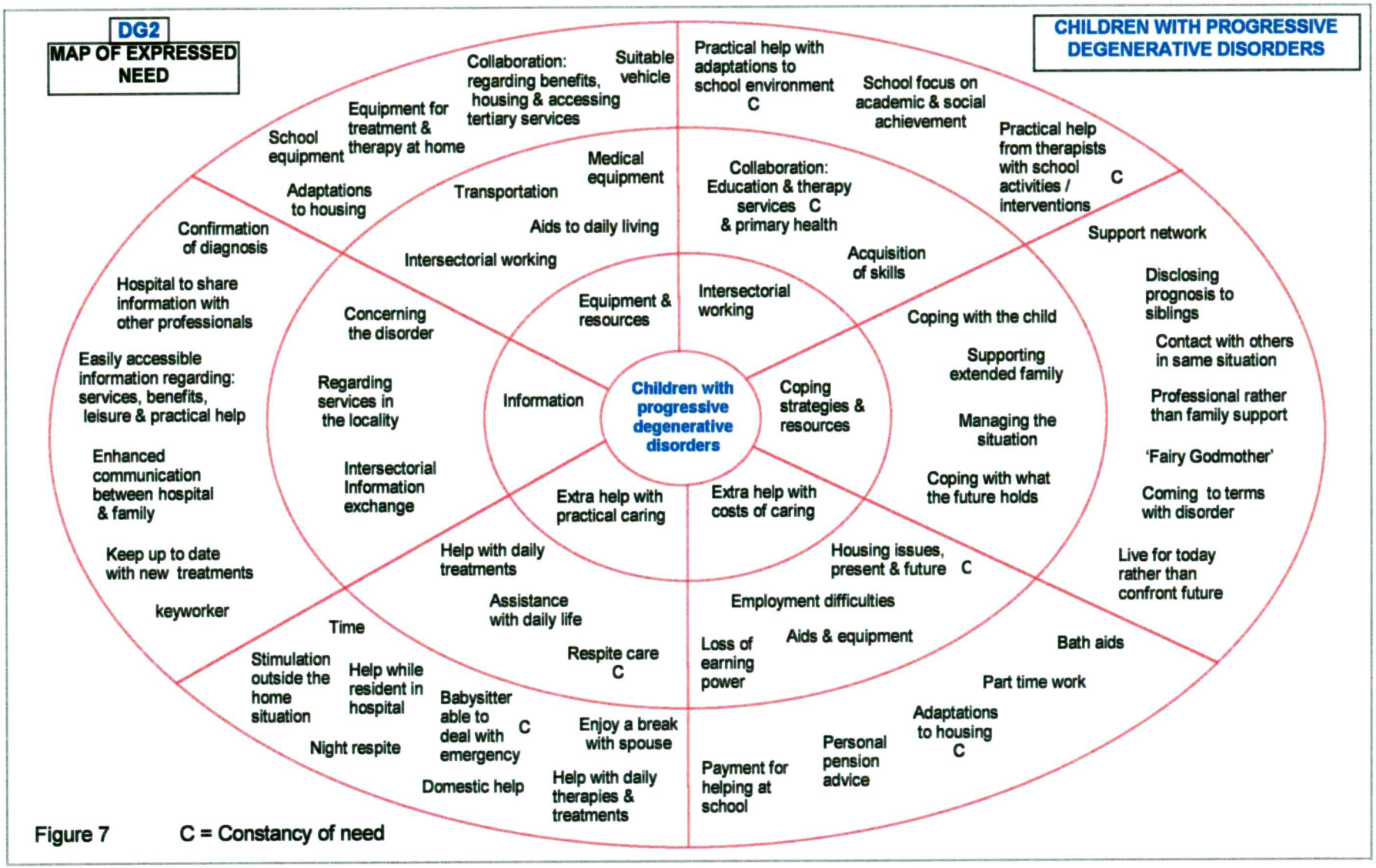


Figure 7 C = Constancy of need

administer treatments and to assist in performing therapies. Equipment is expensive and this was one reason why families expressed the need to try equipment before purchasing to see if it suited their child's needs. Difficulties with transportation were revealed for this group with issues such as the need for more space to accommodate their child's mobility aids and other equipment. A lack of their own transport meant that some families had to rely on public transport for access to hospital and other appointments as well as getting out and about in everyday life. Nevertheless, families with their own transport revealed difficulties with travelling to tertiary centres for outpatient appointments. Accessing the mobility component of the DLA was difficult for families of children nearing 5 years of age with families requesting an improvement in communication processes between services to rectify this.

The need for respite care, assistance with daily life and help with daily care and treatments were higher range of abstraction themes within the Extra Help with Practical Caring Need Zone for this disorder group. Micro analysis of serial data revealed a Constancy of need for respite care particularly for the opportunity to enjoy a break without their child(ren) and with the need for a babysitter able to deal with an emergency medical situation. The respite care which families were already receiving was not always consistent, regular or sufficient to meet their needs. Assistance with managing daily life concerned the need for domestic help and also help while the principal carer (mother) was resident in hospital with the child, a need peculiar to this group. In addition, the need for stimulation outside the domestic situation was also revealed although it is likely that this was perceived as a coping resource which would facilitate better management of the home situation. A need for practical outside help with performing therapies and caring interventions was also identified.

6.8.2.3 Map of Expressed Need: Children with organ failure (DG3) (Figure 8)

This group comprised children with disorders such as cyanotic congenital heart disease, congenital hepatic fibrosis, liver transplantation for biliary

atresia, renal transplantation for nephrotic syndrome, and an undiagnosed disorder resulting in periods of complete respiratory failure.

Educational provision for this group ranged across the services provided in the area. A minority of children in this group attended special schools and had statements of special educational need in place. Families expressed a need for improved communication and information giving processes between their child's school and home. In addition, families also wanted practical speech therapy for their child at school and in the home. Families perceived shortfalls in staffing levels sometimes created an unsafe school environment and therefore expressed a need for their child to be educated in a safe environment at all times.

Within the Coping Strategies and Resources Need Zone families expressed a need for assistance with a variety of issues relating to managing daily life, supporting the extended family and coping with what the future holds. Analysis of serial data revealed a Constancy of need for strategies to deal with future events, in particular with impending life-threatening surgery. A Constancy of need was also demonstrated for resources which could be obtained via a support group or from parents with similarly affected children. Both formal and informal support was requested with some families expressing a need for access to professionals while others felt the need for contact with individual families with similar experiences. Families in this group also perceived the provision or acquisition of information to be an important coping resource. The need for strategies to help extended family members and with informing healthy siblings about the terminal nature of the child's disorder were revealed. However, respondents (mainly mothers) appeared reluctant to express a need for help with marital problems although evidence was implicit in some interviews.

A need for financial assistance with housing issues, aids and equipment were revealed by this group in the Need Zone concerning Extra Help with the Costs of Caring. Serial data analysis revealed a Constancy of need for appropriate housing and adaptations to more comfortably accommodate the

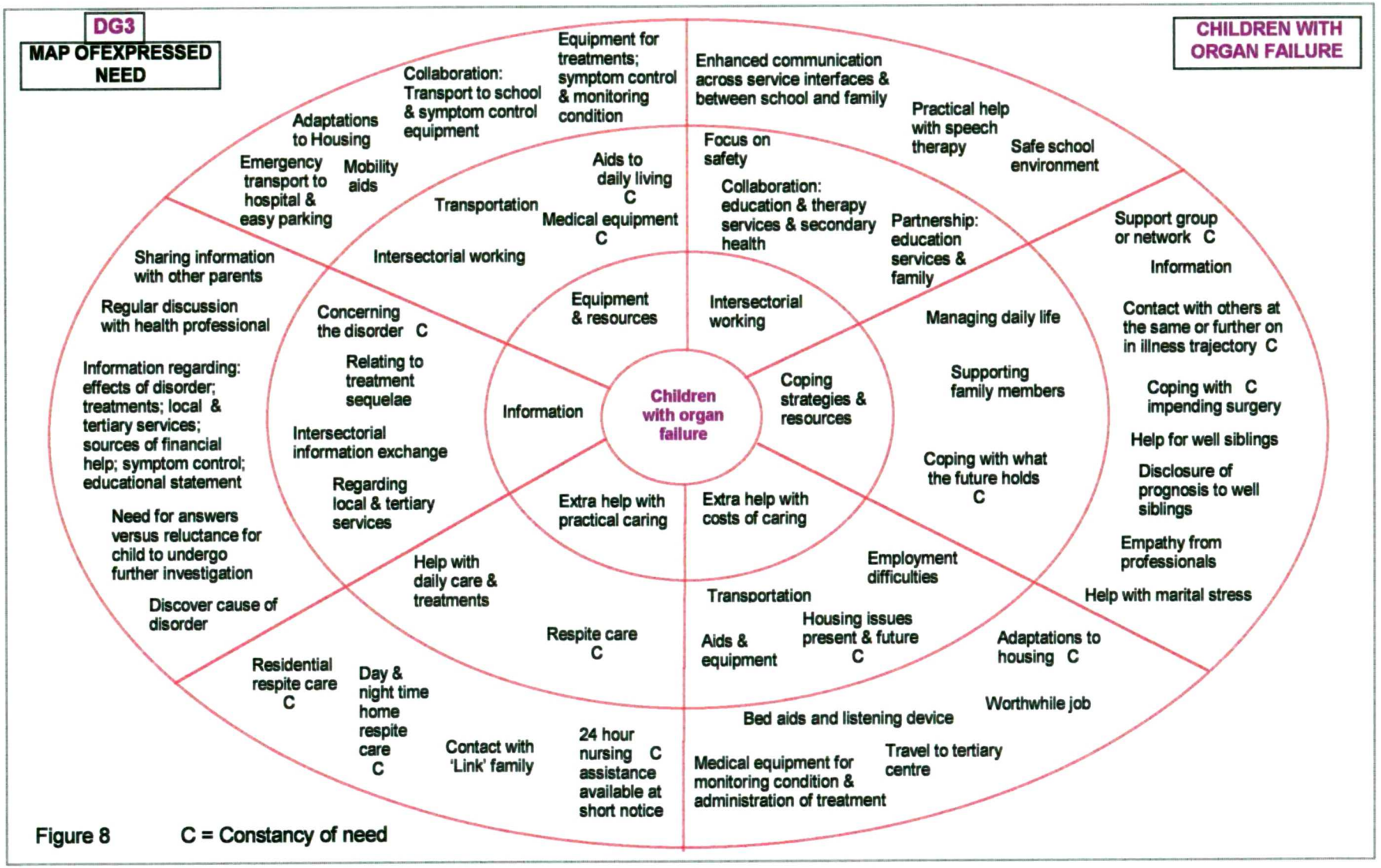


Figure 8 C = Constancy of need

child in the family home. As with the group of children with progressive degenerative disorders (DG2) some families felt the need to plan ahead so that when their child's condition deteriorated adaptations to the home would already have been made. Consistent with families caring for children with progressive degenerative disorders (DG2) families also expressed a need for financial assistance with the purchase of aids for daily living and medical equipment. One mother revealed a reluctance to seek employment for fear that she would have less income than she received with benefits.

Within the Information Need Zone needs were expressed regarding information about the child's disorder, with a Constancy of need being revealed with this requirement. A need for information about helpful services available in the area and tertiary services outside the area of study was also highlighted. Information exchange between the different statutory services was perceived to need improvement. The lack of information about particular disorders and causes was a source of anxiety for families, and the need for information about treatments for the control of distressing symptoms was also expressed. Families also revealed that regular discussion with health professionals would be helpful. Specific information about sources of financial assistance was also needed by families and other information regarding their child's schooling could be obtained from statutory services other than health professionals.

A variety of needs were expressed within the Equipment and Resources Need Zone, in particular, with medical equipment, aids to daily living, issues concerning appropriate transport and for statutory services to develop a collaborative working approach. Micro analysis of serial data illuminated a Constancy of need for medical equipment for the administration of treatments and for symptom control and with the requirement for mobility aids to assist with aspects of daily living in and out of the home. A need for additional help with transport issues concerning emergency admission to hospital and for ease of parking were also revealed, with concerns regarding public transport with journeys to school by bus also being illuminated. Families in this group also expressed a need for respite care and assistance with

performing daily care and treatments. A Constancy of need was revealed for day and night time care and assistance with daily treatments, although such care was not always required from a trained nurse. In addition, the need for extra respite care both in the family home and in appropriate residential establishments was also revealed at each interview period.

6.8.2.4 Map of Expressed Need: Children with profound disability (DG4) (Figure 9)

This disorder group comprised children with profound disability defined for the study as children with no independent mobility and no verbal powers of communication i.e. those with profound physical and leaning difficulties.
At the recruitment interview all children in this disorder group had statements of special educational need in place and attended special schools. Two of the group had full time learning support assistants and the remaining parents felt that their child should have this level of support. Families expressed a need for practical physiotherapy for their child during the course of the school day. Unmet need was also reported with ensuring participation in activities which were enjoyable for their child. Families accepted their child's participation in social skills activities rather than a focus on academic achievement. The need for education in a safe environment was also revealed, families did not want their children to be in physical danger from other children in the special school environment.

The need for help with managing daily life was a prime theme which emerged from the Coping Strategies and Resources Need Zone. The need for more time in the day was evident. Relief from the 24 hour responsibility of caring was also revealed as a way of coping with the situation for all family members, in particular the need to provide adequate time for healthy siblings to participate in their own activities. Consistent with the other disorder groups families also revealed the need for contact with others with similar problems. A need for help with developing strategies for dealing with professionals (particularly school staff) who were not fully conversant with the child's disorder and needs was voiced by families and was peculiar to this group.

Families also wanted regular discussions with health professionals as a way of helping them deal with likely future events.

Within the Extra Help with the Costs of Caring Need Zone families expressed a range of need within four higher range of abstraction themes. These were present and future housing issues, employment difficulties, daily living aids and transportation. Present and future structural adaptations to the family home or the purchase of appropriate one storey accommodation impinged on family finances. Local authority grants were available but families invariably had to contribute a substantial amount of money themselves. Financial assistance was also required for daily living aids. Transport related expense was also revealed and families reported requiring large sums of money to purchase an appropriate vehicle which would accommodate their disabled child, aids and equipment and the rest of the family. Families experienced financial hardship as mothers found it impossible to seek employment because of the associated difficulties of caring for a disabled child.

As in other disorder groups families expressed the need for additional information about aspects of the disability and about services which were available to help them. Information about aspects of the disabilities and prognosis were required so as not to 'just manage'. Analysis of serial data revealed a Constancy of need for information and one family appeared resigned to never having all the information they desired. Other families expressed the need for regular contact with health professionals not necessarily for in depth discussion regarding their child's progress but more for a listening ear from someone who understood and could empathise with their situation. Services which could help them in their practical caring role were desired, in particular, the need for specialist services in the area to avoid the need for travelling to tertiary centres. The lack of knowledge about services or easy access to services located some distance from the family home were factors which caused difficulties.

Within the Equipment and Resources Need Zone families expressed needs which related to aids to daily living particularly with the need for moving,

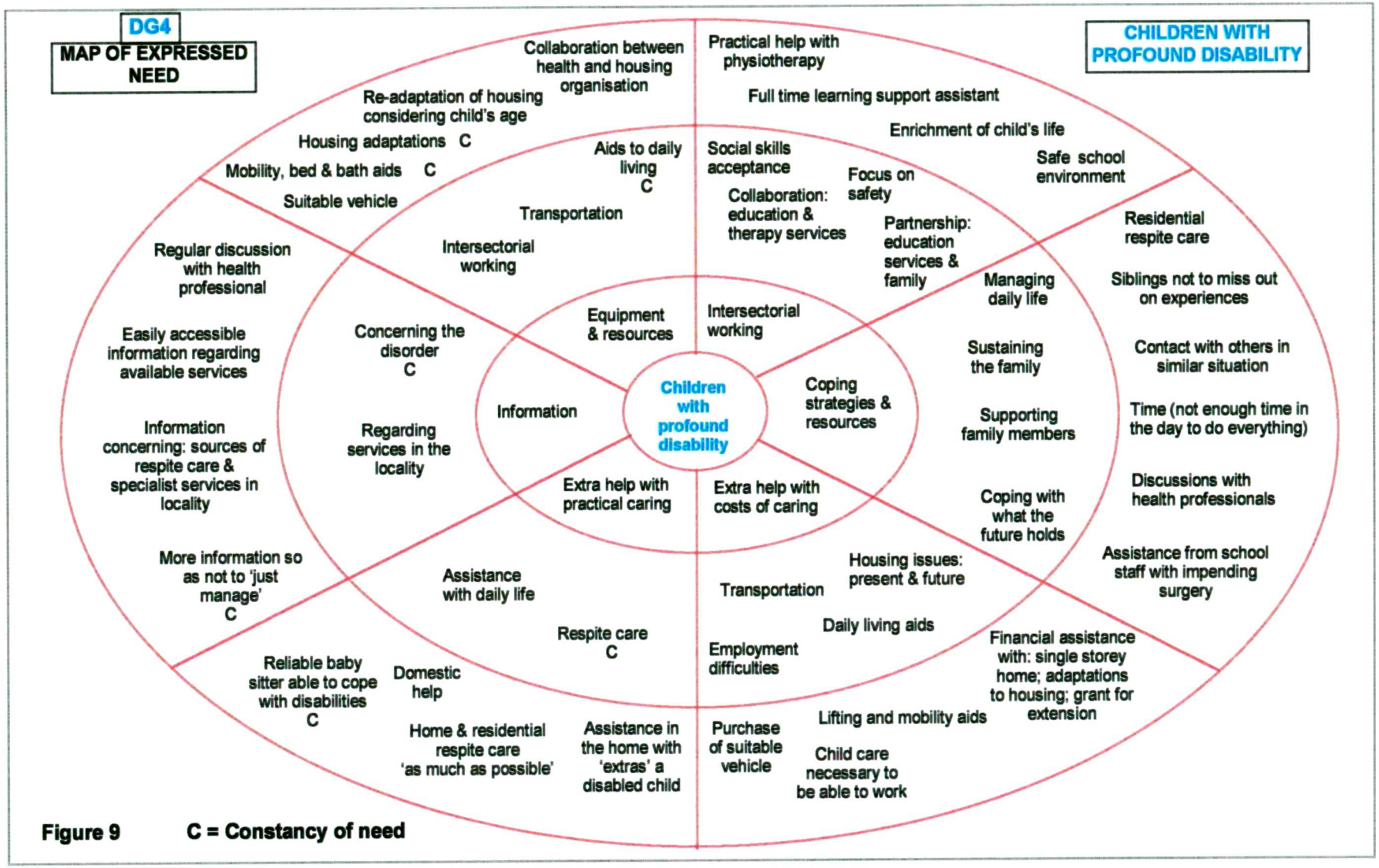


Figure 9 **C = Constancy of need**

handling and mobility aids to deal with large scale movements of the child. Transport difficulties were highlighted which required both practical and financial help and an intersectorial working approach pertaining to the need for structural adaptations to the family home was also revealed. Serial data analysis revealed a Constancy of need for mobility aids and structural adaptations to the family home.

Within the Extra Help with Practical Caring Need Zone as in other disorder groups families expressed a need for respite care and for help with managing daily life. Serial data analysis revealed a Constancy of need for a babysitter able to deal with the complex needs of a profoundly disabled child, for example, someone able and willing to deal with the practical consequences of the disabilities such as moving and handling, feeding and suctioning. A need for any amount of additional respite was revealed, whether large or small. Social services department respite care frequently did not meet the needs of the child or family, although, families were reluctant to criticise for fear of service withdrawal. Families were reluctant to express the need for domestic help in the home possibly for fear of being perceived as unable to cope.

6.9 Micro level of analysis of factors likely to affect the needs of families

6.9.1 Introduction

A variety of factors may influence the extent and type of need for additional help expressed by families, for example, factors such as parental resources, social status and type of housing. However, such structural constraints in which families live out their lives lie outside the legitimate domain of professional CCN practice. Therefore, the following micro analysis of factors which may affect the expressed needs of families pertain to a child's functional and cognitive ability and the need for caring interventions performed by parents. These areas of investigation lie within the field of activity in which caring professionals may be influential.

Significant differences were demonstrated in the comparison of functional ability scores and caring intervention scores (Table 37) between the four disorder groups at Time 1. Such quantitative analysis however, did not reveal how or why the disorder groups differed. The following micro level of analysis of data from interview transcripts, revealed, on an exploratory level, how a number of factors distinguished the disorder groups and were thus likely to influence the family's need for additional help.

Preliminary coding identified eight themes which related to a child's ability concerning activities of daily living (ADLs) and which contributed to the child's level of dependence on their family. A low level of retrievals (i.e. text coded for during the preliminary coding process) were obtained for the group of children requiring intensive medical resources (DG1). Children with progressive degenerative disorders (DG2) also exhibited a low level of physical dependence because all were in the early stages of their illness. All had the potential to become heavily dependent and likely to lose their independent mobility within the next few years. A minority of children with organ failure (DG3) were dependent upon their parents for physical activities such as being lifted in and out of the bath, help with climbing up and down stairs or with mobility outside the home. Children with profound disability (DG4) were totally dependent on their parents and other carers (for example, at school) with all aspects of daily life.

This micro level of analysis of functional ability with ADLs and caring interventions performed by parents generated themes which revealed both commonality and diversity across the disorder groups. Verbatim quotations are used to illustrate theme generation. Appendices 23-32 contain a summary of every incidence of coded text from interview transcripts and should be used in conjunction with this section. The micro analysis of functional ability is reported by ADL for each disorder group. No activity of daily living was perceived as more important than another and the order in which findings are presented is arbitrary.

6.9.2 Children's functional ability

6.9.2.1 Activity of daily living: Mobility

a) Children requiring intensive medical resources (DG1)

No incidences were coded for problems with mobility for children in this group. All were independently mobile and thus no help was required.

b) Children with progressive degenerative disorders (DG2)

Mobility problems for children in this group were as a direct consequence of the illness itself:

> "He does walk independently, but he falls over..... At the moment we try to make him walk as much as possible because if you let him stop walking then he'll lose it quicker. Also it's for his peers. At the end of the day his legs are very tired but I won't take the buggy down to pick him up from school because then he's not normal and he's got to be normal for as long as possible". DG2 F3 T1

> "Regarding mobility, she walks unaided but she falls over a lot". DG2 F9 T1

> "We've got to watch him because some days he falls more he can't do the stairs properly, we've got to help him and hold his hand to go up and down the stairs. .... He can't jump. He doesn't do things that the other children does, you know running". DG2 F6 T1

c) Children with organ failure (DG3)

For children with organ failure difficulties with mobility were associated with other symptoms related to their particular disorder:

> "If we go out anywhere he goes in his pushchair 'cos he can't walk for a long distance or anything without getting really out of breath". DG3 F3 T1

> "The last time he was at the hospice, (senior nurse) said to me, he walked from the play room into her office and she said he was so

> breathless, I asked if he had been running, and she said no. He had just got up and walked from here to there". DG3 F5 T2

> "I'm not bothered that she can't walk. .... We've been told (by tertiary centre) until she has her full repair that she will be behind development wise, because she hasn't got the energy to do these things". DG3 F1 T1

d) Children with profound disability (DG4)

Lack of independent mobility was illuminated for children with profound disabilities:

> "Well she shuffles around on her knees at home, she's never wheelchair bound at home, only when she's at school and when we go out". DG4 F2 T1

> "She's wheelchair bound the whole time". DG4 F4 T1

6.9.2.2 Activity of daily living: Eating

a) Children requiring intensive medical resources (DG1)

Although children in this group ate unaided they frequently displayed a poor appetite, while for children with allergy problems the need for close monitoring at mealtimes was evident:

> "She's not very good at eating at the moment. She just picks. She's gone off her food". DG1 F8 T1

> "Well at home I wouldn't give him any supervision but if he was eating anywhere else other than at home he would need 100% supervision". DG1 F7 T2

b) Children with progressive degenerative disorders (DG2)

A lack of appetite was also revealed with children in this group with mealtimes being described as a major cause of difficulty with trying to tempt the child to eat:

"I try and encourage her to use a spoon and a fork more but, she finds it easier with fingers. But she's five now .... I don't expect her to cut it up ..... but she just forgets". DG2 F4 T3

"He feeds himself when he feels able to and I have to fork-feed him if he gets tired of an evening. He can't be bothered to put it in his mouth". DG2 F1 T1

"She can feed herself quite adequately, but she won't eat, this is the problem." DG2 F7 T2

c) Children with organ failure (DG3)

Families caring for children in this group perceived their child's eating habits to be problematic with a poor appetite also being frequently reported:

"He eats by himself but he doesn't eat a great deal, he has a poor appetite. He's on a dairy free diet and has calcium supplements. It's so erratic his appetite, we have a few days where he eats well then he doesn't seem to eat anything for days on end". DG3 F6 T2

"It is only about a week now that I've got her off the jars of food, she is 16 months now and I just feel she should be eating has much of our food as she can. I realise she's not a normal size or weight for feeding yet. She is gradually getting on to our food, but I'm still having to put it in the blender". DG3 F1 T1

d) Children with profound disabilities (DG4)

Mealtimes for children with profound disabilities were reported as time consuming as all the children needed to be fed. One child was fed via a gastrostomy tube while another had periods when her diet needed to be supplemented with a naso-gastric feeding regime:

"She can't feed herself at all, (child) is totally spoon-fed". DG4 F2 T1

"She needs to be fed. She eats and chews really nicely. It does take her longer to eat then everyone else, I mean, breakfast can take half an hour, dinner can take an hour or so, so it's quite time consuming". DG4 F1 T1

"She has four boluses (liquid food supplement via gastrostomy tube) during the day, they do two at school, and the pump at night.....She will (eat by mouth) if she's in the mood but otherwise she just spits everything out and a lot of it goes down into her lungs as well so it's best to give her just a little bit by mouth so she has a taste and her mouth doesn't get dry and sore, but her main calories come through the tube". DG4 F3 T1

6.9.2.3 Activity of daily living: Eliminating

a) Children requiring intensive medical resources (DG1)

Enuresis and bowel problems were revealed for children in this group:

"She's fine, but now and again she does wet the bed". DG1 F4 t1

"Well, bowels are usually a bit diarrhoeay but at (tertiary centre) they said that was because of his general level of allergy". DG1 F7 T2

"He's got a nasal spray (for nocturnal enuresis) for when he goes away, we haven't tried it yet 'cos one of the side-effects could be feeling sick". DG1 F6 T3

b) Children with progressive degenerative disorders (DG2)

Similarly, children in this group were also reported as having difficulty with bladder and bowel control:

"It's getting worse (enuresis), during the day, wee and poo. We're having a bit of an uphill struggle with that". DG2 F3 T2

"She wets at night, she wears a nappy". DG2 F9 T1

c) Children with organ failure (DG3)

The majority of children in this group did not experience problems with eliminating, although one child with learning disabilities was doubly incontinent and for another it was easier for child and parents for the child to wear nappies at night:

"We are still in night time nappies. He was out of them six months ago and getting up to use the potty and getting tied up in his wires (equipment for monitoring condition), we ended up with bent wires and (child) just got cross. ..... He was unplugging it when he was pulling and the alarm was going off and we just said this is ridiculous and put him back in nappies". DG3 F6 T2

"He wears nappies all the time. We're trying, you know. He sort of understands to go to the toilet and that but he just seems to - well we're trying!" DG3 F3 T1

d) Children with profound disability (DG4)

All children in this group were doubly incontinent, although caring strategies were employed by families to encourage normal function:

"She's doubly incontinent. Although she tries a little. She tries to hold on and we can time her as well so that we get about 90% of her bowel movements and quite a lot of her urine really". DG4 F2 T1

"She's incontinent and wears nappies the whole time, she does do a poo on the loo though". DG4 F1 T1

6.9.2.4 Activity of daily living: Skin integrity / ability to turn self

a) Children requiring intensive medical resources (DG1)

Skin problems for children in this group related to the general level of atopy which they experienced:

"His skin gets red when he's eczematous you know, and his eczema's up a bit at the moment. Sometimes he makes a fuss about taking his evening primrose oil and you can tell if he doesn't take it, he really does start to dry out". DG1 F1 T1

b) Children with progressive degenerative disorders (DG2)

Few problems were reported by respondents in this group although their child's limited mobility in bed necessitated the need for help with turning at night:

"She's always woken up. She went in her bed last August and I've noticed it more since then. Whether it's because she's getting bigger and heavier and she can't just roll herself over, whereas when she was a baby she perhaps just did it". DG2 F4 T1

c) Children with organ failure (DG3)

No skin problems or need for pressure area relief were noted for this group.

d) Children with profound disabilities (DG4)

As with children with progressive degenerative disorders (DG2) the lack of independent mobility led to the need for pressure area relief particularly at night for children with profound disability:

"She doesn't move in the night at all, but she's got a sheepskin under-blanket, ...a sheet, then a sheepskin on top of the sheet, but we found that she was wetting through everything quite a lot after the gastrostomy tube was put in. ..... We got some thicker nappies which are better but we've also got a pad what we put on now as well. ..... but she gets sore sometimes, she has had sores where she's rubbed her skin and that". DG4 F3 T1

"She's quite capable of turning herself but she kicks the bed clothes off which matters a lot in the Winter so we have to keep an eye on that". DG4 F2 T1

"She's OK (child's skin integrity) as long as we move her around a lot. She's just got one place at the base of her spine that often gets quite sore, but we're aware of it and we seem to be managing with it". DG4 F4 T1

Specific skin problems related to stoma care:

"She gets sore around the stoma (tracheostomy), this may be when she gets wet from swimming for instance, we're looking into that at the moment because it's been rather nasty recently. If the dressing isn't changed enough it can get very sore round there". DG4 F2 T1

6.9.2.5 Activity of daily living: Moving and handling

a) Children requiring intensive medical resources (DG1)
b) Children with progressive degenerative disorders (DG2)

No problems were reported with moving and handling issues by families caring for children in these groups.

c) Children with organ failure (DG3)

Only one child in this group required major assistance with moving and handling:

> "Yeah, we have to lift him in and out (of the bath). Which is heavy. Normally it's me (mother) who does the bathing, lifting him in and out of the bath. He'll (father) do it occasionally, but (child) can't do it himself". DG3 F3 T2

d) Children with profound disability (DG4)

Their lack of independent mobility resulted in movement and handling problems for all children in this group:

> "It makes me laugh because at school she need two people to lift her but I have to do it by myself, she's a two man lift apparently and I'm here on my own". DG4 F1 T1

> "It's better to have two people to lift her, although when (father) is out and she needs a bath I do it by myself, but she's quite big, over five stone now". DG4 F3 T1

6.9.2.6 Activities of daily living: Hygiene and dressing

a) Children requiring intensive medical resources (DG1)

Independence with hygiene and dressing needs were a function of normal age and development for children in this group, with children less than seven

years of age generally needing supervision and assistance with bathing, while older children demonstrated their need for privacy:

> "She (4 year old) dresses herself but I have to put her shoes on, she can't do laces". DG1 F4 T1

> "He's fine (hygiene needs) as far as I know. He (teenager) wouldn't say, he's starting to lock the door when he goes to the bathroom now!" DG1 F2 T3

b) Children with progressive degenerative disorders (DG2)

Hygiene and dressing needs were also related to age and normal development for this group although respondents reported that their children generally needed some assistance:

> "She hates having a wash, ... it's like invading her. .....It's actually when you're doing something to her, like when I'm combing her hair and it's all over the place I find that hard to do. These children have much greater strength than equivalent children of their own age, we have to work hard to keep her pinned down. I usually try to talk to her about something else, distract her, or we just do it quickly. That works best really". DG2 F9 T1

> "He doesn't really wash himself at all. So you have to go in there and say 'put some water up there' and whatever else". DG2 F1 T2

> "She can put her vest on and she can put T-shirts on that have got quite large neck openings. She can't put sweat-shirts on because they're too heavy for her to lift her arms up. ....She can take knickers and trousers off but it takes an awfully long time. She just has to lay on the floor and keep rolling from side to side and pulling a little bit down". DG2 F4 T1

c) Children with organ failure (DG3)

A minority of children in this group required major assistance with meeting their hygiene needs, while others required some help and supervision. Respondents reported that their children could do more than they actually did with regard to getting dressed but that they didn't have the time or inclination to let their children do things for themselves:

"He needs a lot of help (in the bathroom). He only washes a bit, bites the toothbrush, but not brushing that sort of thing". DG3 F5 T1

"He's beginning to do a bit for himself, he undresses himself more than dressing but he is starting, when I've got the time and patience!" DG3 F6 T2

d) Children with profound disability (DG4)

All children in this group were incapable of meeting any of their own personal hygiene and dressing needs and therefore totally dependent upon their parents or other carers for such care and attention:

"Well it's (bathing child) becoming more difficult, we used to have an upright bath seat but we found that I couldn't manage any more because I was worried about my back. So now we've bought one which we lower into the bath and I can manage quite well, but I must admit if (father) is here it's very helpful to have him to wash her hair because of the trachy (tracheostomy)". DG4 F4 T1

"One person can do the actual bathing but to get her in and out easily or fairly easily you need two (people)". DG4 F2 T1

"She is getting more wind swept (lopsided sitting position) because of the hip, and she's had a sore on her, ... right hip where the brace is rubbing. So I have had to put a dressing on. And she didn't wear the brace on Saturday, because I didn't want to put it on because of the dressing, but without it she's absolutely hopeless.". DG4 F1 T2

6.9.2.7 Activity of daily living: Sleeping

a) Children requiring intensive medical resources (DG1)

No problems with sleeping were reported by respondents caring for children in this group apart from those children who woke with nocturnal enuresis.

b) Children with progressive degenerative disorders (DG2)

Similarly, no problems were revealed in this group with sleep problems apart from the child who woke frequently at night needing to be made comfortable:

> "If she doesn't wake me (mother) up I don't get up and turn her over, but she more than likely wakes, two, three, four times a night is quite normal. .... So I just turn her over and she's asleep again before I've even got to her bedroom door and I'm asleep again before my head hits the pillow. It's not as if I'm woken up and then awake half the night. But it is a broken nights' sleep". DG2 F4 T1

c) Children with organ failure (DG3)

Half the children in this group were reported to exhibit problems with sleeping which were related to symptoms of their disorder:

> "He has two pillows propped up a bit to breathe easier and he's very restless, he's always tossing and turning and moaning all night". DG3 F3 T1

d) Children with profound disability (DG4)

A minority of children in this group demonstrated sleep problems and required assistance during the night:

> "She's no better at night, I don't know what it is 'cos she's alright when you go in and talk to her. She just screams the place down until you do". DG4 F3 T2

> "I turn her before I go to bed, but she can still move herself, she can go from side to side in her sleep so she's not too bad". DG4 F1 T1

6.9.2.8 Activity of daily living: Communicating

a) Children requiring intensive medical resources (DG1)

Children in this group were not reported to have any difficulty with communicating their needs and wants.

b) Children with progressive degenerative disorders (DG2)

All children in this group were able to express themselves fully within their family situation, although a minority required therapy to assist their speech development:

> "She communicates pretty well at home, there's no doubt as to what she wants". DG2 F7 T1

> "He copies his brother most of the time, but he's got his own way to talk not everyone can understand him. Only me, not even sometimes his Dad because I am the one who always looks after them. ..... (Health visitor) saw him and they were concerned with it (level of speech), every time she has been here she hasn't heard them talking that is why she referred them both to the speech therapy sessions". DG2 F6 T1

c) Children with organ failure (DG3)

A large majority of children in this group had difficulty in expressing themselves. Four were having speech therapy:

> "No (he can't indicate all his needs verbally) not all the time. We use Makaton signs as well sometimes. I don't know too much, but I know some. We sort of like understand each other to a certain extent, you know - mother's instinct". DG3 F3 T1

> "He gets his message across although it's only single words. He doesn't sign, although he understands things. Having said it's single words, it's getting to be 2-3 words. We've got a private tutor involved and he has made quite considerable progress". DG3 F5 T1

d) Children with profound disability (DG 4)

All children in this group had major communication problems. Two had no methods of communicating their needs with the remainder having very limited non-verbal communication. However, families reported that all children were able to signify happiness or displeasure:

> "Communication wise, they've tried all kinds of things at school and we've been to various language centres and they haven't really convinced me that (child) has just got the capability of what we'd normally call communication. ..... Communication aids to (child) seem to be toys really

and she'll play with them but she won't use them for the practical use that they were intended". DG4 F1 T1

"Well she can't speak but I know what she wants, I mean we as a family seem to know what she needs, I mean (sibling) will come in and say oh mummy (child) wants a drink, so you can generally tell why she's upset, usually if (child) is upset there is a reason, because she is a happy child really". DG4 F1 T1

"It's probably me wishful thinking really, that I know what she wants, but I know, she's got a different sort of cry if she's tired or uncomfortable or I don't know, she probably cries and I check everything anyway and I go through her nappy, give her a drink and that sort of thing and if it works it's probably pot luck really, but I think I know what she wants". DG4 F3 T1

"With (child) she's either happy or sad so she obviously communicates with us in that way. But apart from that it's just trial and error or it's just experience, we've come to know 'cos if she's unhappy there is always a reason so you find out what it is and then she is OK again or obviously if she is unwell, you can't really do anything about it". DG4 F4 T1

6.9.3 Caring interventions performed by parents

6.9.3.1 Introduction

Preliminary coding identified ten themes associated with caring interventions performed by parents as they looked after their child on a daily basis. Appendices 33-42 contain a summary of every incidence of coded text from interview transcripts concerning caring interventions performed by parents and should be used in conjunction with this section. Presentation of findings is by theme (Box 1) with verbatim quotations being used to illustrate commonality and diversity among the disorder groups.

Box 1 Caring interventions by parents: Higher range of abstraction themes
• Caring processes • Practical interventions exceeding normal parenting responsibilities • Additional caring burden • Additional caring burden on mother • Parents sharing the additional caring responsibilities • Coping with additional demands of practical interventions • Developing expertise with the illness • Additional parental concerns • Co-ordination role • Managing the competing demands of two affected children

6.9.3.2 Caring interventions: caring processes

A principal theme common to all disorder groups concerned caring processes which families employed. Families in all groups observed, assessed and made decisions and choices on a daily basis about their child's care and treatments:

> "Before we could just ring and take them (to the hospital ward) but now we have to go through the GP which makes it worse because the GPs got totally different ideas to the hospital. One's not so bad now because when (older child) was smaller he came round and said give him Ventolin but four hours later (child) was in intensive care. Now if he comes he asks me if I want him in hospital! So he's changed. But the others if they can't hear a wheeze they think they're all right". DG1 F6 T1

> "In the past he had some really bad green noses and .....he got a very bad cough after it. But if I gave an extra 15 minutes physio before he went to sleep at night, after a period of about five or six days then the cough subsided and it disappeared". DG2 F1 T1

> "At the time we believed the hospitals were comparing notes and it would be two different consultants views and they'd sort something out. But ....they were actually against each other and it made us feel terrible. ..... Then it came down in the end to a choice as to whether we wanted (child) to go to (local hospital) or (tertiary centre) which was a very difficult choice to make. We plumped for (local hospital) because it was nearest and when (child) needed treatment he needed it then and not in two hours time". DG3 F6 T1

"I wouldn't ever give her any more (than the agreed amount of drug to control a seizure) I'd take her to hospital so that they could give her something intravenously". DG4 F4 T1

Families across the groups except for children requiring intensive medical resources (DG1) demonstrated a problem solving approach to care:

"We only used to test (urine sample) once a day when she was in remission but then it got to be easier to test morning and night because we always found that her ( ) level showed up more in the morning than at night when she was going to go into relapse (this is opposite to other children with same disorder)". DG3 F4 T1

"Sometimes you give her suction 15 times on the go, but we try to let her cough up as much as possible because her coughing reflex is better than it was. It's difficult to get a balance because sometimes the more you suction the more you produce". DG4 F4 T1

Deciding when to administer extra drug therapy or treatments to deal with an emergency situation was evident in all disorder groups:

"We do count the breathing, but then I don't always remember how fast is fast anyway. I tend to hit them quite hard with nebulisers straight away and that sometimes stops them getting so bad. I know you're not supposed to but you do just keep doing one more nebuliser". DG1 F6 T1

"We give it to her if she's chesty (oxygen) and it helps her if she gets into one of these long fits". DG4 F2 T1

6.9.3.3 Caring interventions: Practical caring interventions exceeding normal parenting responsibilities

Administration of drugs was a practical caring intervention performed by almost all parents in all disorder groups:

"In the last six months I've had to take him to the doctors twice and he's had to have six days of prednisolone and the nebulisers both times". DG1 F1 T2

"I don't give them to him whole (the capsules) I open them up as I don't think he'd swallow them. .....and he still has the liquid vitamins and antibiotics". DG2 F1 T2

"We tried bribery when he first went on it (new drug)..... The first time I gave it to him he just shuddered. ..... The minute he sees the bottle and the syringe he starts to cry. .... We had about three days of him hiding as soon as he saw the bottle, we had to sit on him, tea-towel round him so it didn't go on his clothes if he spat it out and make him take it. By the time we'd finished I was in tears, he was in tears, but I think it's worked he's now accepted that he has got to take it. .....If it is going to stop the apnoeic spells then it is worth it, but if it is not then it is just making my life hell to be honest". DG3 F6 T2

"She still has her alternate days enemas and the (drugs) for her spasm and pain in her hip". DG4 F1 T2

In addition, except for parents of children requiring intensive medical resources (DG1) all disorder groups maintained medical equipment used for both monitoring their child's condition and the administration of treatment and / or therapies:

"He can do it (set up the gastrostomy feed), but I do it for him because if I leave it to him it would be too late and then he'd be too tired. When it's finished the buzzer goes off and he wakes up and I go and disconnect it and flush it through and everything". DG2 F5 T1

"Physically (since giving oxygen via concentrator at night) he is a lot more rested and he is not so out of breath. His colour is a lot different he isn't as blue. .... It has made a difference to him, he is so peaceful". DG3 F3 T2

"When she wakes in the morning her secretions are usually quite thick and she needs to be suctioned at least six times. ....We always give saline before feeding as that often clears her so she doesn't keep coughing throughout her feed". DG4 F4 T1

All groups performed practical caring tasks which pertained to activities of daily living, although particular activities were specific to each group. No caring interventions for ADLs were revealed for children requiring intensive medical resources (DG1). For families of children with progressive degenerative disorders (DG2) practical caring interventions revolved around mobility, feeding and communication:

"He gets quite a lot of cramps .....and he gets pain and his tendons go really hard at the back. The only thing we can do is just stretch and do

> an exercise and then the cramps just goes. It is harder a night because the pain is more and lasts longer". DG2 F6 T3

> "She's still seeing the speech therapist. She has got all the sounds there it is just the mind and the brain getting them the right way round, so we help her with those sorts of things most days". DG2 F4 T3

Tasks related to communication were revealed in the group of children with organ failure (DG3):

> "He's still making progress (with speech) even in the last three weeks, the speech therapist has tried something new, like putting endings on words, and he's actually doing it when we practice it with him, not every word, not every sound, but he's making the effort to do it". DG3 F5 T3

However, practical caring interventions concerning all ADLs were undertaken by all families caring for profoundly disabled children (DG4) although interestingly, a relatively low level of retrievals of incidences were obtained from the preliminary coding. A possible reason for this may have been because these interventions were performed daily as part of their family routine and thus considered ordinary and not worthy of elaborate description.

> "We give her vitamin supplements, but that's not prescribed, because her diet being rather limited, with all her food needing to be pureed so that she can take it off the spoon". DG4 F2 T2

> "It is better (with lifting aid) but you still have to lift to put her in the sling. The only problem is when you get her out of the bath, if you hoist her back across, it soaks everywhere and it ends up soaking her bed". DG4 F3 T2

Practical caring interventions which were specific to the disorder groups were:

a) Children requiring intensive medical resources (DG1)

The administration of chemotherapy, blood sampling for monitoring condition and the maintenance of an emergency drug pack at home and school:

> "We have got one (an emergency drug pack for anaphylactic shock), and we are going to take that box to the school so that they have got one". DG1 F1 T2

"I thought it was a bit much that I had to ask, but (nurse specialist) did apologise saying she was too busy and couldn't have shown us before (how to perform a finger prick blood test). It seems silly to me it should be automatic that they teach us, after all I did the bloods from the Hickman Line and that's much more technical. It should be part of the package". DG1 F5 T2

b) Children with progressive degenerative disorders (DG2)

This group achieved the highest number of retrievals (portions of text coded for caring interventions) and incidences reflected a wide variety of practical caring interventions related to all ADLs and to requirements of the specific disorders e.g. chest physiotherapy for children with CF. No caring intervention was specific to this disorder group.

c) Children with organ failure (DG3)

The specific practical caring task performed in this group involved resuscitation practices:

"He's had one (spell) since then (starting new drug treatment) but he came round quickly, we just had to pick him up and he was out of it, no bagging (with re-breathing bag) or oxygen". DG3 F6 T2

d) Children with profound disability (DG4)

Suctioning via a tracheostomy and dealing with epileptic seizures were revealed as a specific caring intervention by parents of children in this group:

"If (child) has a really bad infection it's not unusual to suck her out once every five minutes - we've had 60 catheters over the morning in the waste basket". DG4 F2 T1

"We agreed with the doctors that she needs 10mgs (drug to control seizure in an emergency) because 5mg didn't do anything or we would give her 5 and then wait 10 minutes and she would always need another 5 so we all agreed with the doctors that we may as well just give her 10 and on occasions after half an hour I have actually had to give another 10 and that's always worked". DG4 F4 T1

6.9.3.4 Caring interventions: Additional caring burden

Caring interventions which were burdensome for families differed across the disorder groups, although families of children with organ failure (DG3) and profound disability (DG4) demonstrated similarities in that interventions revealed were those which required attending to their child during the night and those which reflected a Constancy of care:

> "He has (sedation) which he has at night to help him sleep, cos he's constantly on the go. And even then he still don't sleep all night, anyway. He always gets up quite a few times". DG3 F3 T1

> "We have to get up and tuck her up and make sure she's not trying to pull herself through the top of the cot and making herself very uncomfortable. We have to move her down every so often. So we're always looking at her at night, when we wake up we go and see what she's like". DG4 F2 T2

Problems with encouraging children to eat were also illuminated:

> "He refuses to drink milk and now he only has it on cereal and in a cup of tea. Because he's never had eggs, he has no cheese and so no calcium going in so they put him on the supplements. Which is just another job for us to do isn't it?". DG3 F6 T1

Performing physiotherapy was described as a caring burden for families of children with progressive degenerative disorders (DG2):

> "People say why don't you shift the midnight physio forward, but I mean that physio is pretty important actually. It is disruptive, it's horrible to have to come home from an evening out and do physiotherapy, but I think that midnight session is very important, particularly when she's got a cold, she's just lying in one position for so long, that stuff gets a chance for infection to set in". DG2 F7 T2

In addition, the need for therapies to maintain independent mobility were revealed as onerous:

> "He gets lots of cramps and sometimes we have to carry him when we're out and he is getting quite heavy now". DG2 F6 T3

For families of children requiring intensive medical resources (DG1) living with the possibility of their child experiencing a life-threatening crisis which would necessitate them initiating appropriate life-saving action was a burden which families described:

> "We don't carry it if we go to the shops, which maybe we should, but we have to take it with us when we go on holiday and things like that". DG1 F3 T1

> "I am extremely careful and take no chances ever. I attend parties and take his own food in his own box, that sort of thing". DG1 F7 T2

During an acute exacerbation of the illness which necessitated the provision of continuous care for more than a 24 hour period was also revealed as a burden:

> "It is hard doing it 24 hours, especially as they (episodes) last so long. I mean (older child) was ill from Thursday, right through to Tuesday. He was very low. He'd had four hourly nebulisers and on Sunday he's had them three hourly, which I shouldn't have been doing". DG1 F6 T1

6.9.3.5 Caring interventions: Additional caring burden on mother

Predominately, the caring interventions which appeared to reflect the caring burden on mothers were common to all disorder groups. Issues such as the responsibility for undertaking practical caring tasks during the day and getting up to the child at night were revealed across the disorder groups except for children with profound disabilities (DG4):

> "My husband deals with it totally different to me. He can't understand why I sit here worrying all day, but I'm the one sitting at home watching and waiting to see how bad they get. Whereas when he gets home- I know he has to cook their tea and everything when I'm at work, but he's only got one maybe two nebulisers to do then put them to bed. And then I do the nights". DG1 F6 T1

> "I generally hear her and get up. If I don't hear her then he (child's father) hits me and then I get out. On occasions that he does do it, she won't let him help her anyway. She says I want my mummy. So it's pointless him going to her. I don't like him staying away because she's

never going to get used to him doing it but at the same time if he does it she won't just turn over and go back to sleep". DG2 F4 T1

"It has been suggested that when his asthma is bad we have someone here for a while to nebulise him over night and things but I don't think he (child) would take it. He even objects to Daddy getting up to him". DG3 F6 T2

The burden on mothers caring for profoundly disabled children (DG4) was most evident with ADLs such as moving and handling:

"It makes me laugh because at school she needs two people but I (mother) have to do it by myself (lifting and handling child at home)". DG4 F1 T1

"I (mother) can manage on me own, but I'd rather not, 'cos I've still got to lift her from the bath to the bed and that sort of thing". DG4 F3 T1

6.9.3.6 Caring interventions: Parents sharing the additional caring responsibilities

Mothers were principal carers in all but one family participating in the study. Examples of fathers sharing aspects of the caring role were not frequently cited, although fathers in all four disorder groups did help with some practical caring interventions:

"My husband comes home at 4.15 and three evenings I go (to work) at 4.15. Although it's the wrong time of the day I don't see (older child) that much, at least I haven't got to worry about other people looking after them". DG1 F6 T1

"My husband does it (children's exercise regimen) because with me it doesn't work so well..... We do only once in the evenings when my husband gets home from work". DG2 F6 T1

"She can have really dramatic mood swings (sequelae of drug treatment). .... My husband finishes work early to help put them to bed. The other day he said I don't know what's wrong with (child). .... she's just lying in bed. And I said, I'll finish what I'm doing and then I'll go in and if she's not suitable I shan't send her to school tomorrow. I went in and you wouldn't have believed it she was just as happy as anything". DG3 F4 T1

6.9.3.7 Caring interventions: Coping with the additional demands of practical interventions

Families in all groups except profoundly disabled children (DG4) demonstrated ways in which they coped with the practical demands of care. A common theme revealed in all three groups related to strategies which were used for learning to administer drugs, dealing with drug and treatment compliance problems, and coping with the complexity of drug regimens:

> "He gets fed up with taking his medicine, and occasionally he rebels. A few weeks ago we found out he was not taking his preventative and taking the 'treater' more, ... he would take a few puffs but half an hour later he needed some more. We stopped all that and took everything away and started again. .....We decided not to do anything about it because when he went to the clinic he was so scared that he was going to get into trouble and was quite frightened about it". DG1 F1 T2

> "We have a chart on the wall and each day we cross them off. With us working shifts it is difficult to remember which day is which". DG1 F5 T1

> "It depends what we put the drugs in. If we put them in blackcurrant he's adamant he's got coke so that's fine". DG3 F6 T1

Several families caring for children with CF revealed strategies they utilised to administer pancreatic enzymes:

> "We open the capsules and sprinkle the balls on yoghurt, but he used to have the powder sprinkled on his breakfast cereal". DG2 F5 T1

> "We used to have a syringe without a needle, the powder used to dissolve vaguely, ... and squirt it into the back of his throat. Then he had little pellets in banana and then when he want to school we bribed him with a large quantity of Lego ..... and he's sorted his own way of doing it with opening the capsule up". DG2 F8 T1

> "Well, we have to bribe her usually. I mean it is not unknown before a meal to bribe her with chocolate to take the enzymes and then give her, her meal, but she's crafty because she knows that we'll give in to her eventually, she has to have something with the enzymes". DG2 F7 T1

6.9.3.8 Caring interventions: Developing expertise with the illness

With the experience of caring for their child families in all disorder groups became experts with the particular caring interventions which their child required:

> "I just get a feeling about the neb - if they're not lasting four hours in between. I just get the feeling I'm not winning. ..... I go on the cough - how bad the cough is. I don't know, I just sort of know - it's difficult to explain". DG1 F6 T1

> "When you've sort of lived with a child for two and a half years, I think you get a feel for things (how many physio sessions child needs during the day)". DG2 F7 T2

> "We always know when she is going to go into relapse. It's always been the case and we always know when she's going because if the morning's (test) the highest she'll be going for relapse". DG3 F4 T1

> "I cannot see how you can be (sleeping) upstairs with a child sleeping there (in downstairs bedroom extension) with a tracheostomy because you've got to be alert and you've got to have your ear trained for the least danger sign when your child's got a tracheostomy". DG4 F2 T1

6.9.3.9 Caring interventions: Additional parental concerns

Families in all groups except profoundly disabled children (DG4) expressed concerns regarding the care and treatment which they performed for their child. Concerns common to the groups related to the administration of drugs, with some families caring for children requiring intensive medical resources (DG1) worried about giving an injection in an emergency situation:

> "It does worry me 'cos I've never given anyone an injection before. And to do it under those conditions (stressed in an emergency). I did have some training with the oranges but that was over a year ago now". DG1 F3 T1

> "But you know this is more of an emergency thing, it could come at anytime, they'll (school staff) will have to act before actually phoning me.....I think anything in this emergency kit the stipulation's got to be

> that it's got to be administered by someone trained. I don't want (child) to have to do this. If he needed it a teacher should be with him and make sure he's not going unconscious and make sure that he takes it properly". DG1 F1 T1

Families caring for children with progressive degenerative disorders (DG2) were more concerned with the dosages and strengths of the drugs which they were giving to their child:

> "We were on the strong stuff but there is a scare on at the moment so we are on these which is rather a nuisance because he has to take rather a lot of them. ..... the other stuff was much better he didn't have stomach aches, which is silly because that's what they're worried about, it's annoying because he gets stomach ache with these. One feels like demanding that he have the old stuff back". DG2 F8 T1

Worries regarding the sequelae of their child's drug treatments were revealed by families of children with organ failure (DG3):

> "I think he's more frustrated with them introducing the (new drug treatment), ... he's actually full of energy, bounding around, but it's very difficult to curb at times when we want him to sit quietly. Like at mealtimes he's up and down in his chair which he didn't used to do". DG3 F6 T2

Worries concerning specific practical caring interventions other than those pertaining to drug administration were identified in all groups except in children with organ failure (DG3):

> "We went for a couple of lessons at the hospital. But it was too much to remember. I couldn't remember if I had to do it (physiotherapy) before or after the nebulisers. It was the opposite to what I thought ..... I kept getting in a muddle so I don't do it". DG1 F6 T1

> "You know they have colds just about all the time in the Winter so it's going to be more or less a full time job going into school to do physio. It's going to be very wearing and likely to completely dominate family life. I'm not looking forward to that". DG2 F7 T1

> "Once it (stoma) gets chapped it's difficult to get back to normal again. If she goes swimming and they get a lot of chlorinated water around it and if the dressing comes off and they don't notice then you get a rough patch on the tracheostomy and that causes it to be inflamed". DG4 F2 T2

Difficulties obtaining medical equipment were a cause for concern for families of children with progressive degenerative disorders (DG2) and children with organ failure (DG3):

> "We started fund-raising last year to buy an electric one (wheelchair) .... and we were very lucky - someone gave us a second-hand one and they didn't charge us for it. But we still need to carry on fund-raising 'cos it is about eight years old". DG2 F4 T1

> "Dr (Hospital consultant) was supplying them but he's on a research grant and the money ran out. We had to go to the ward and let us have like one, and (child) sometimes wears it all day and it got wet or dirty and was no good. I had to ask for more than one, because they're made for premature babies, he gets out of bed in the morning and he only needs to stand on it and it's broken. I got quite a complex about asking for them. I was made to feel that they should last longer". DG3 F6 T1

Worries about the need for future treatments were specific for families caring for children with progressive degenerative disorders (DG2):

> "We did go and see the surgeon and he said that is in the future, he said we have to wait and see how they are getting on". DG2 F6 T3

Concerns specific to families of children with organ failure (DG3) related to the child's integration into the local community for the enhancement of social skills:

> "The thing that we're concerned about at the moment is now he's nearly 12 he won't be going to (local primary school) anymore and the integration programme they have is really good so we don't know what is going to happen now about him mixing with others in the community". DG3 F5 T3

Difficulties concerning professionals were revealed by families of children with organ failure (DG3) and children with profound disability (DG4):

> "That took a lot of pressure off, knowing we are actually going to see someone who actually knows what they are talking about. It makes me very angry to think that (child) has gone through hell and back for someone's self confidence, self pride, ... 'cos we all make mistakes but why make a mistake with a child's health. I dreaded going to see Dr (new consultant) but it was the best day I ever had. That's all I wanted anyone to say, someone to admit that she was a problem". DG3 F4 T2

"I think over half term I felt quite swamped because I had quite a few. I had the OT out on Friday, I had (social worker) out on Thursday, I had the physio yesterday. It seems to be all at once and when you've got the other children as well, with all the other things that you have to do. It is quite overwhelming". DG4 F1 T2

6.9.3.10 Caring interventions: Co-ordination role

Families in all groups co-ordinated their child's care with and between the various health service sectors:

"We went to (hospital consultant) three weeks ago and they said they would write to the doctors (GPs), so I suppose when the doctors (GPs) get the letter they'll write a prescription, if I haven't heard anything when he goes back to school I'll get in touch with them". DG1 F1 T2

"We have appointments (with tertiary centre) every six months. But if we needed to go up in the meantime for her callipers then we would do that, 'cos obviously a lot of it depends on their growth. But I can just ring them you know if I need to". DG2 F4 T2

"We have to take it (suction machine for repair) to the clinical workshop (at hospital). As long as you can reassure him you've got a requisition from (Community Trust) he's happy to do it". DG4 F2 T1

Liaison with voluntary organisations was revealed in all groups except by families of children requiring intensive medical resources (DG1):

"I'm after a new one (physiotherapy aid) 'cos I need something higher and he's bigger. We can probably go through (person who coordinates local charity) for that because she runs a loan service. It would be good to swap over this one for one of her tables". DG2 F5 T1

"We're down to about nine sessions (holistic exercise regime) and he definitely can't manage an hour because he physically gets so tired ..... People (volunteers from the village) still come in because he enjoys the company and so from that point of view we keep it on". DG3 F5 T1
"We bought that one (portable suction machine) and we've got a second one on loan from ACT (Aid for children with tracheostomies charitable organisation)". DG4 F2 T1

Families caring for children with progressive degenerative disorders (DG2) and organ failure (DG3) undertook co-ordination of their child's care with their child's school:

> "I took all these pills with me, these nebulisers and showed them (school) what it involved - they just didn't believe it! They didn't realise what he did go through". DG2 F5 T1

The co-ordinator role for families of children requiring intensive medical resources (DG1) and with progressive degenerative disorders (DG2) involved co-ordination of care requirements with and between health and other statutory organisations:

> "Then they gave us the wrong needle. The least helpful was the local pharmacist. He would not try and get me one with a short needle, even though I'd found the stock number from the hospital and phoned him up with it, telling him who was distributing it and he would not have anything to do with it. I was furious. Because I was already fed up with the way things were going but that was the last straw". DG1 F3 T1

> "She (physiotherapist) can't always get there (school), she goes in about once a week just to keep an eye to see how he is and if there's anything untoward she'll report back to me and then I get the teachers to do it (physiotherapy) for him. There's a couple of teachers that know how to do it". DG2 F5 T1

6.9.3.11 Caring interventions: Managing the competing demands of two affected children

There were families with two affected children in all groups except in the profoundly disabled children group (DG4). No issues concerning caring interventions were revealed by families of children with organ failure (DG3) but issues relating to equipment, drug management and physiotherapy were identified by families of children requiring intensive medical resources (DG1) and with progressive degenerative disorders (DG2):

> "They've only been very bad together once and I don't know whether that was better or worse. Now it's one starts and gets better and then the other starts, so like it lasts a lot longer and then I sort of have a big list of who has what and when. In the night I'm thinking which one's

sitting in here waiting for a nebuliser, how much am I supposed to give you. Trying to keep awake enough to concentrate on what I'm doing. I laugh afterwards but at the time it's awful". DG1 F6 T1

"Because of (younger child being diagnosed) she (physiotherapist) said it would be a good idea for him to start (swimming) as well, so I was taking them both together. He is quite confident in the water with (physiotherapist), so she takes care of him and I take care of (older child)". DG2 F6 T1

6.10 Summary

The micro level of analysis of expressed need data revealed a diversity of need among the disorder groups and the development of the four Maps of Expressed Need demonstrated the unique nature of each disorder group within the six original need domains. The first step in the mezzo level of analysis revealed core themes common to all disorder groups which offered a unifying and recurrent picture of the needs of families and reflected a truer image than the original need domains. The core themes were identified as: intersectorial working; coping strategies and resources; extra help with the costs of caring; extra help with practical caring; information and equipment and resources. Analysis of serial data revealed examples of Constancy of need in all disorder groups with children with organ failure (DG3) revealing unmet need in all Need Zones except the Intersectorial Working Need Zone.

A micro level of analysis of data pertaining to functional ability and caring interventions performed by parents identified common factors which may affect the needs of families. Further analysis revealed commonality and diversity among the disorder groups of potential influences on family need.

Chapter 7 The Continuing Care Needs Of Families - Mezzo And Macro Levels Of Qualitative Analysis

7.1 Introduction

Findings from mezzo and macro levels of analysis are reported in this chapter. Mezzo analysis concludes with the production of models for each of the six Need Zones exploring the relationship between expressed need and factors which may affect families' need for additional help. Findings from the macro analysis are used to illustrate the development of the Map of Family Need which presents the needs of families caring for a child with a LTI regardless of the diagnosis.

7.2 Mezzo level of analysis of children's functional ability

A mezzo level of analysis of themes derived from data concerning the child's functional ability revealed common factors likely to affect family need as well as factors specific to each disorder group.

Diversity between the disorder groups was particularly noticeable with mobility issues. A full range of mobility on a dependence / independence continuum was demonstrated. For example, children requiring intensive medical resources (DG1) were fully mobile while at the other end of the spectrum children with profound disability (DG4) had no independent mobility. For children with organ failure (DG3) mobility difficulties were caused by other symptoms associated with their disorder whereas children with progressive degenerative disorders (DG2) experienced mobility problems as a direct consequence of their illnesses. Interestingly, and as might have been anticipated with this disorder group, a deterioration in mobility was noted over the study period.

The common factor across the disorder groups concerning eating related to children having a poor appetite, with mealtimes being described as difficult or problematic. Diversity among the groups was most evident in the comparison

between children requiring intensive medical resources (DG1) who were able to eat independently and those children with profound disability (DG4) who needed to be fed either by spoon or artificially. Parents in this disorder group reported that this was a very time consuming ADL.

Common factors among the disorder groups relating to elimination were nocturnal enuresis problems, with caring strategies and interventions performed as a consequence of double incontinence by families of children with profound disabilities (DG4) evident. The incontinence problems of one child with organ failure (DG3) were related to the degree of learning disability rather than the LTI itself.

No common problems associated with skin integrity and the need for pressure area relief were revealed. Although children with progressive degenerative disorders (DG2) and profound disability (DG4) were similar in that a lack of mobility conferred the need for parents to employ pressure relieving strategies especially at night.

Parents of all children requiring intensive medical resources (DG1) and progressive degenerative disorders (DG2) and the majority of children with organ failure (DG3) did not experience problems with moving and handling their child. Thus, the lack of need for additional help was the principal common feature regarding this ADL. Lack of independent or limited mobility influenced the need for mechanical assistance with caring interventions involving moving and handling for children with profound disability (DG4). No family caring for a child with profound disability had an aid (hoist) at Time 1, while two families were still without such an aid by Time 3. Only half of the group had bath aids which facilitated washing, moving and handling by reducing the need for large scale movements in and out of the bath.

With the exception of children requiring intensive medical resources (DG1) all other groups were reported to need some form of assistance with hygiene and dressing. Those children with moderate or profound learning disabilities in the groups of children with organ failure (DG3) and profound disability

(DG4) required major help or were totally dependent on their family for these aspects of care.

Surprisingly few difficulties were reported with issues related to sleeping across all the disorder groups. Thus, this lack of need for additional help conferred commonality rather than diversity with this ADL.

A full range of communication levels were demonstrated across the four disorder groups. Children requiring intensive medical resources (DG1) had full powers of verbal communication while children with profound disability (DG4) had none or very limited forms of non-verbal communication. A certain degree of commonality was demonstrated as families helped their children with speech therapy in all disorder groups except DG1.

7.3 Mezzo level of analysis of caring interventions performed by parents

Ten higher range of abstraction themes were generated from the micro level of analysis of the 'caring interventions' data which demonstrated the additional duties undertaken by parents exceeding the responsibilities of normal parenting. Commonalities and diversity among the disorder groups are presented in Table 51.

Commonality among disorder groups relating to caring interventions likely to affect the needs of families were revealed within themes concerning caring processes, parental sharing of additional caring responsibilities, developing expertise with their child's illness and with a co-ordination role. All disorder groups demonstrated practical caring interventions exceeding normal parenting responsibilities, however, analysis showed that these related to ADLs which were specific to each disorder group. All groups except those families of children with profound disability (DG4) revealed concerns about drug administration, while further analysis revealed diversity with the areas of concern. The additional caring burden on mothers regarding moving and handling issues was revealed solely for children with profound disability

(DG4) while the development of strategies to administer pancreatic enzymes was specific to children with progressive degenerative disorders (DG2) within the theme concerned with the additional demands of practical interventions.

Table 51 Thematic commonality and diversity in caring interventions among disorder groups

Higher range of abstraction theme	❖ Factors common to disorder groups	♦ Factors specific to disorder groups
Caring processes	❖ Assessment ❖ Observation ❖ Make decisions ❖ Make choices ❖ Problem-solving approach (except DG1) ❖ Administration of extra drug therapy or treatments in an emergency	
Practical caring interventions exceeding normal parenting responsibilities	❖ Caring tasks pertaining To activities of daily Living (ADL) ❖ Administration of drugs ❖ Maintenance of medical equipment	♦ DG1 None ♦ DG2 Mobility, Eating, Communicating ♦ DG3 Communicating ♦ DG4 All ADLs ♦ DG1 Chemotherapy, blood sampling, maintenance of emergency drug pack ♦ DG3 Resuscitation procedure ♦ DG4 Tracheostomy suction, treatment of seizures
Additional caring burden	❖ DG3 & DG4 Attending to child at night; constancy of care; encouraging child to eat	♦ DG1 Living with potential LT crisis; constancy of care in acute episodes ♦ DG2 Chest physiotherapy; therapies to maintain mobility
Additional caring burden on mother	❖ Responsibility for practical caring tasks ❖ Attending to child at night	♦ DG4 ADLs such as moving and handling
Parental sharing the additional caring responsibilities	❖ Mothers principal carer (except in 1 family) ❖ Some help from fathers with interventions	

Table 51 (Cont.)

Coping with the additional demands of practical interventions	❖ Strategies for learning to administer drugs ❖ Dealing with drug & treatment non-compliance ❖ Coping with complexity of drug regimes (except DG4)	♦ DG2 Strategies to administer pancreatic enzymes
Developing expertise with illness	❖ All experts with particular caring interventions needed	
Additional parental concerns with caring for a child with a LTI	❖ About drug administration (except DG4) ❖ About specific practical caring tasks (except DG3) ❖ DG2 & DG3 Difficulties obtaining medical equipment ❖ DG3 & DG4 Difficulties with professionals	♦ DG1 Administration of injection in emergency situation ♦ DG2 Dosages and strengths of drugs ♦ DG3 Sequelae of drug treatments ♦ DG2 Need for future treatments ♦ DG3 Integration into local community
Co-ordination role	❖ All co-ordinators of their child's care ❖ Liaison with voluntary organisations (except DG1) ❖ DG2 & DG3 Co-ordination of care between home and school ❖ DG1 & DG2 Co-ordination of care within and between organisations	
Managing competing demands of two affected children		♦ DG1 Issues relating to sufficient equipment & drug management ♦ DG2 Physiotherapy

7.4 Mezzo level of analysis of factors likely to affect expressed need

7.4.1 Introduction

The identification of core themes common to all disorder groups contributed to the creation of six Need Zones (6.8.1; Table 50). Analysis of middle range

of abstraction themes of expressed need (6.2 - 6.7 Appendices 5-22) revealed a number of factors likely to influence a family's need for additional help. These are presented in the following six boxes by individual Need Zone with disorder group identification (DG).

7.4.2 Identification of factors likely to affect family need

Box 2 Factors in the Intersectorial Working Need Zone
♦ Competency of non-health professionals in dealing with potential LT crisis (DG1) ♦ Quality of care co-ordination: inter-sector (health); inter-agency (DG1) ♦ Availability of specialist therapists (DGs2;3;4) ♦ Quality of special needs education (DGs2;4) ♦ Quality of care co-ordination: partnership between home and school (DGs2;3) ♦ Quality of information exchange: between professionals and family (DG3) ♦ Level of environmental safety (DGs3;4)

Box 3 Factors in the Coping Strategies & Resources Need Zone
♦ Availability of external coping resources (DGs1;2;3;4) ♦ Level of parental coping strategies (DGs1;2) ♦ Availability of professional help with developing coping strategies (DGs2;3)

Box 4 Factors in the Extra Help with Costs of Caring Need Zone
♦ Accessibility of benefits (DG1) ♦ Flexibility of employment (DGs1;2) ♦ Availability of additional monetary resources (DGs2;3;4) ♦ Security of future financial status (DG2) ♦ Employment opportunities (DG3) ♦ Availability of specialist child care (DG4)

Box 5 Factors in the Extra Help with Practical Caring Need Zone
♦ Accessibility of respite services (DGs1;2;3;4) ♦ Availability of additional support with family life (DGs1;2;4) ♦ Availability of assistance with practical caring (DGs2;4) ♦ Constancy of care (DGs2;3;4) ♦ Accessibility of home nursing services (DG3)

Box 6 Factors in the Information Need Zone
♦ Quality of information exchange between family and services (DGs1;2;3;4) ♦ Level of parental participation (DGs1;2;3;4) ♦ Degree of care co-ordination (DG2) ♦ Quality of intersectorial information exchange (DG2) ♦ Degree of social network (DG3)

Box 7 Factors in the Equipment and Resources Need Zone
♦ Accessibility of equipment loan service (DGs1;2;3;4) ♦ Quality of care co-ordination: inter-sector (health); inter-agency (DGs2;3;4) ♦ Suitability of caring environment (DGs2;3;4) ♦ Suitability of transport (DGs2;3;4) ♦ Accessibility of aids loan service (DGs3;4)

7.5 Macro level of analysis of factors likely to affect expressed need

7.5.1 Introduction

Mezzo analysis of themes generated from the micro level of analysis of the child's functional ability, need for caring interventions and expressed need data identified commonalities and diversity among the four disorder groups. Factors likely to affect family need which were common to all disorder groups and across all need zones were revealed:

- Rarity and life-threatening (LT) nature of the disorder
- Functional ability of the child regarding activities of daily living (ADLs)
- Cognitive ability of the child
- Extent of caring interventions performed by parents

In addition, there were also common factors influencing the level of need specific to four of the need zones:

- Availability of external coping resources
- Accessibility of respite care services
- Quality of information exchange
- Level of parental participation
- Accessibility of equipment loan service

7.5.2 Development of models for the Need Zones

Models (Figures 10-15) were developed by grouping the expressed needs from the outer ellipse of the four disorder group Maps of Expressed Need (Figures 6-9) within the six Need Zones. This level most closely reflected the summary of expressed need generated from verbatim quotations of families. Placing these together facilitated comparison across the disorder groups. The central ellipse in each Need Zone contains the factors common to all disorder groups which are likely to affect a family's need for additional help. The mezzo level of analysis of factors have been placed within the middle ellipse. The four segments contain the expressed needs of each disorder group and while factors affecting need are frequently described in more than one group the combination of factors in each group differs thus reconfirming the uniqueness of the disorder groups.

7.5.2.1 Intersectorial Working Need Zone (Figure 10)

A range of factors likely to affect need in the Intersectorial Working Need Zone were evident (Box 2). Commonality across the disorder groups with any one factor was not demonstrated although the extent to which specialists in the services allied to medicine (physiotherapy, speech therapy, occupational therapy) were available was a common factor in all groups except for children requiring intensive medical resources (DG1). The quality of or extent to which a child's care was co-ordinated across the provider services was also evident in three of the four groups (exception: children with profound disability (DG4).

7.5.2.2 Coping Strategies and Resources Need Zone (Figure 11)

The extent to which external coping resources (i.e. support group, respite care, information and suitable childcare) were available for families in all groups affected their level of need and was therefore considered a common factor which may affect family need for additional help (Box 3). The degree of internal coping strategies demonstrated by parents which had developed through their experiences with their child or other life events was also a

Figure 10

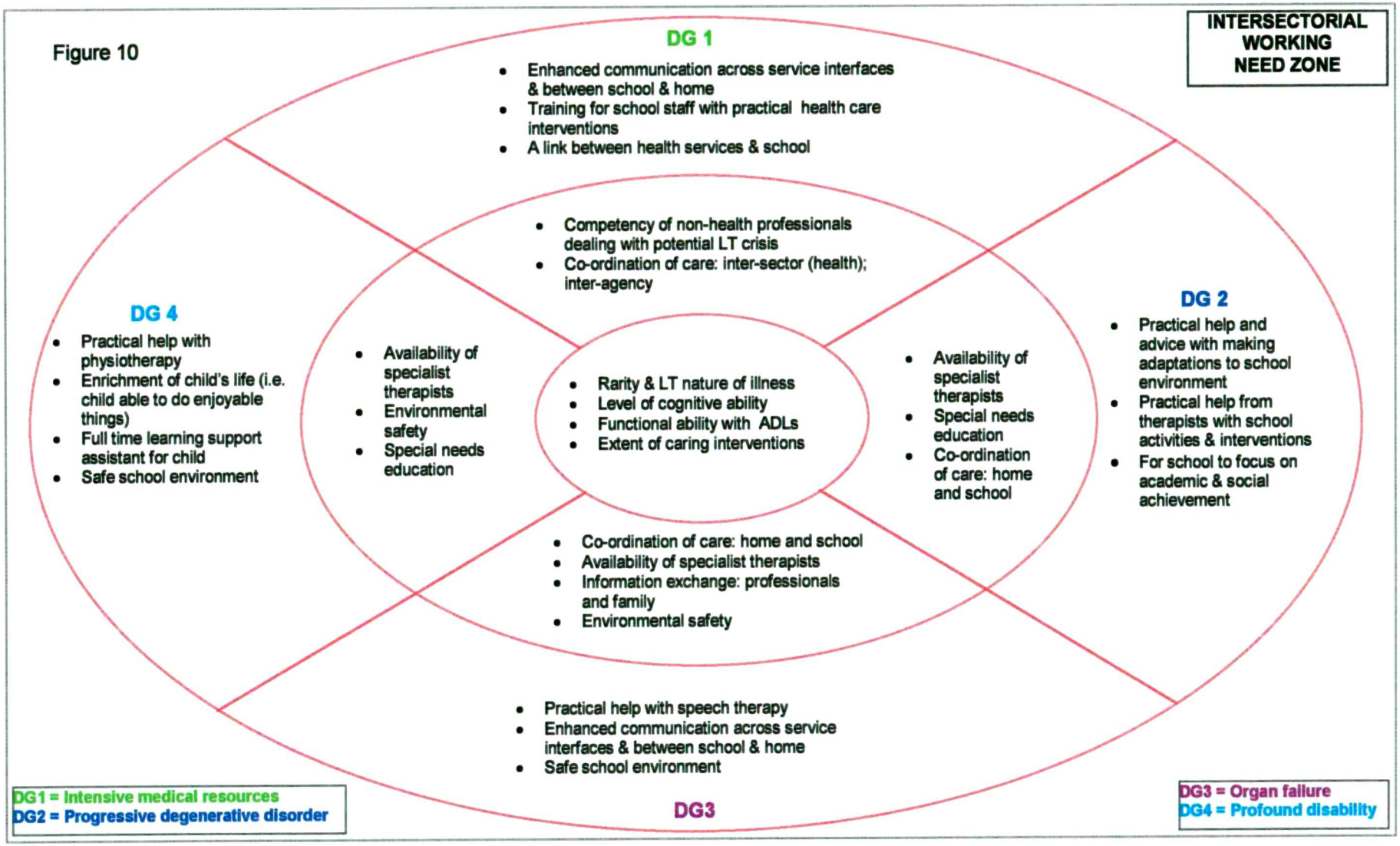
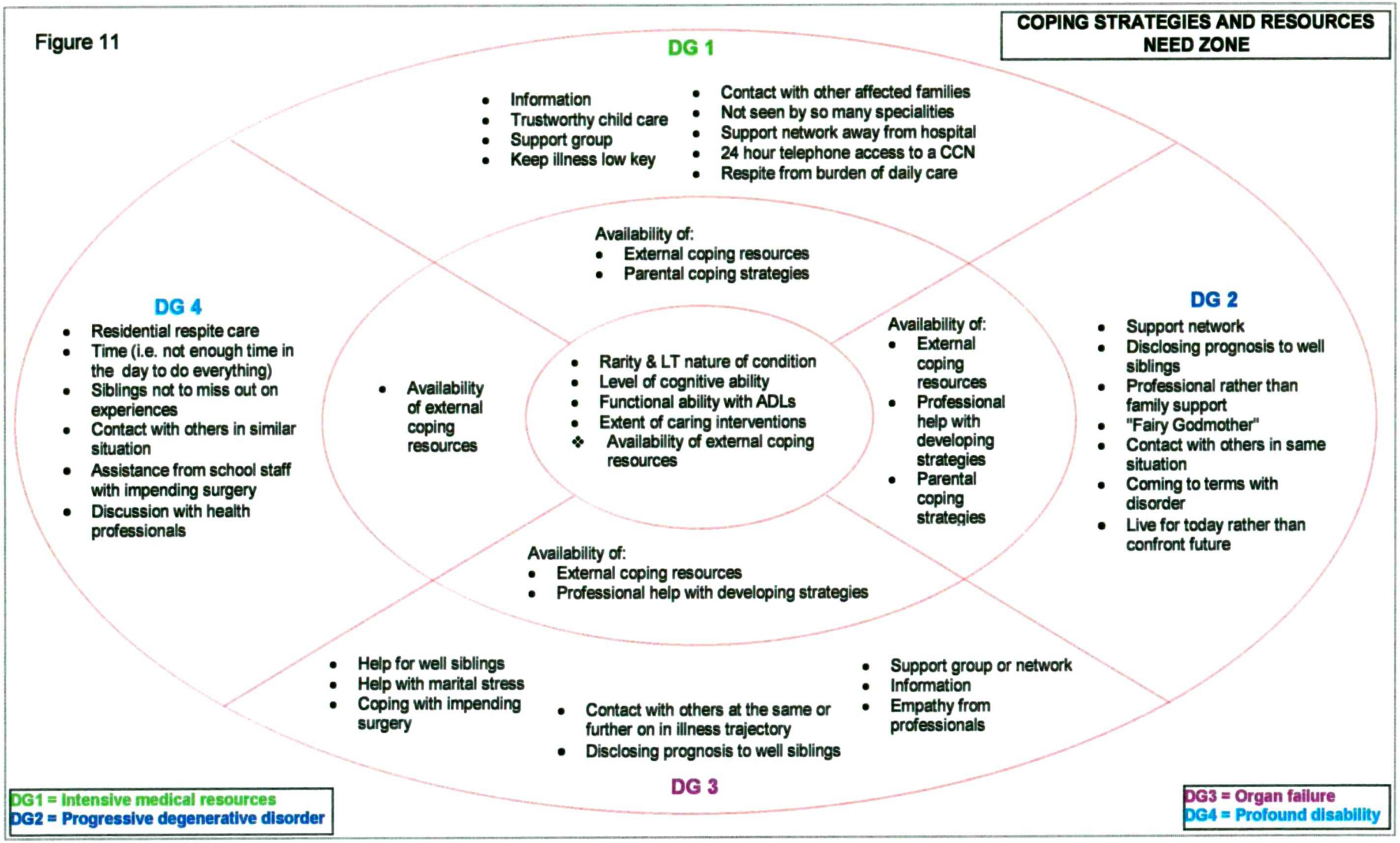

INTERSECTORIAL WORKING NEED ZONE
DG 1
Enhanced communication across service interfaces & between school & home
Training for school staff with practical health care interventions
A link between health services & school
Competency of non-health professionals dealing with potential LT crisis
Co-ordination of care: inter-sector (health); inter-agency
DG 4
Practical help with physiotherapy
Enrichment of child's life (i.e. child able to do enjoyable things)
Full time learning support assistant for child
Safe school environment
Availability of specialist therapists
Environmental safety
Special needs education
Rarity & LT nature of illness
Level of cognitive ability
Functional ability with ADLs
Extent of caring interventions
Availability of specialist therapists
Special needs education
Co-ordination of care: home and school
DG 2
Practical help and advice with making adaptations to school environment
Practical help from therapists with school activities & interventions
For school to focus on academic & social achievement
Co-ordination of care: home and school
Availability of specialist therapists
Information exchange: professionals and family
Environmental safety
Practical help with speech therapy
Enhanced communication across service interfaces & between school & home
Safe school environment
DG3
DG1 = Intensive medical resources
DG2 = Progressive degenerative disorder
DG3 = Organ failure
DG4 = Profound disability

Figure 11


COPING STRATEGIES AND RESOURCES NEED ZONE
DG 1
Information
Trustworthy child care
Support group
Keep illness low key
Contact with other affected families
Not seen by so many specialities
Support network away from hospital
24 hour telephone access to a CCN
Respite from burden of daily care
Availability of:
External coping resources
Parental coping strategies
DG 4
Residential respite care
Time (i.e. not enough time in the day to do everything)
Siblings not to miss out on experiences
Contact with others in similar situation
Assistance from school staff with impending surgery
Discussion with health professionals
Availability of external coping resources
Rarity & LT nature of condition
Level of cognitive ability
Functional ability with ADLs
Extent of caring interventions
❖ Availability of external coping resources
Availability of:
External coping resources
Professional help with developing strategies
Parental coping strategies
DG 2
Support network
Disclosing prognosis to well siblings
Professional rather than family support
"Fairy Godmother"
Contact with others in same situation
Coming to terms with disorder
Live for today rather than confront future
Availability of:
External coping resources
Professional help with developing strategies
Help for well siblings
Help with marital stress
Coping with impending surgery
Contact with others at the same or further on in illness trajectory
Disclosing prognosis to well siblings
Support group or network
Information
Empathy from professionals
DG 3
DG1 = Intensive medical resources
DG2 = Progressive degenerative disorder
DG3 = Organ failure
DG4 = Profound disability

contributing factor for families of children requiring intensive medical resources (DG1) and with progressive degenerative disorders (DG2). The extent to which professionals were available to provide assistance with developing and enhancing parental coping strategies was a common factor among families of children with progressive degenerative disorders (DG2) and organ failure (DG3).

7.5.2.3 Extra Help with Costs of Caring Need Zone (Figure 12)

The extent to which families in all disorder groups except for children requiring intensive medical resources (DG1) had additional monetary resources available to them influenced their level of need for extra help (Box 4). This was implicit in DG1 where access to state benefits was revealed as a factor likely to affect need. The degree of employer flexibility affected both parents, but particularly those mothers who were either in work or who wanted to gain employment and was revealed in all disorder groups except for children with profound disabilities (DG4). Issues such as the opportunity to have time off at short notice for illness or to attend hospital appointments with their child were factors which affected gainful employment.

7.5.2.4 Extra Help with Practical Caring Need Zone (Figure 13)

The accessibility and availability of respite care was a factor which affected families' need for additional help and was common to all disorder groups in this Need Zone (Box 5). Other factors were common to three of the four disorder groups. These were the amount of additional support available to assist with daily life in the home (children requiring intensive medical resources, with progressive degenerative disorders and profound disability DGs 1, 2 & 4) and the constant nature of the caring burden (children with progressive degenerative disorders, organ failure and profound disability DGs 2, 3 and 4).

Figure 12

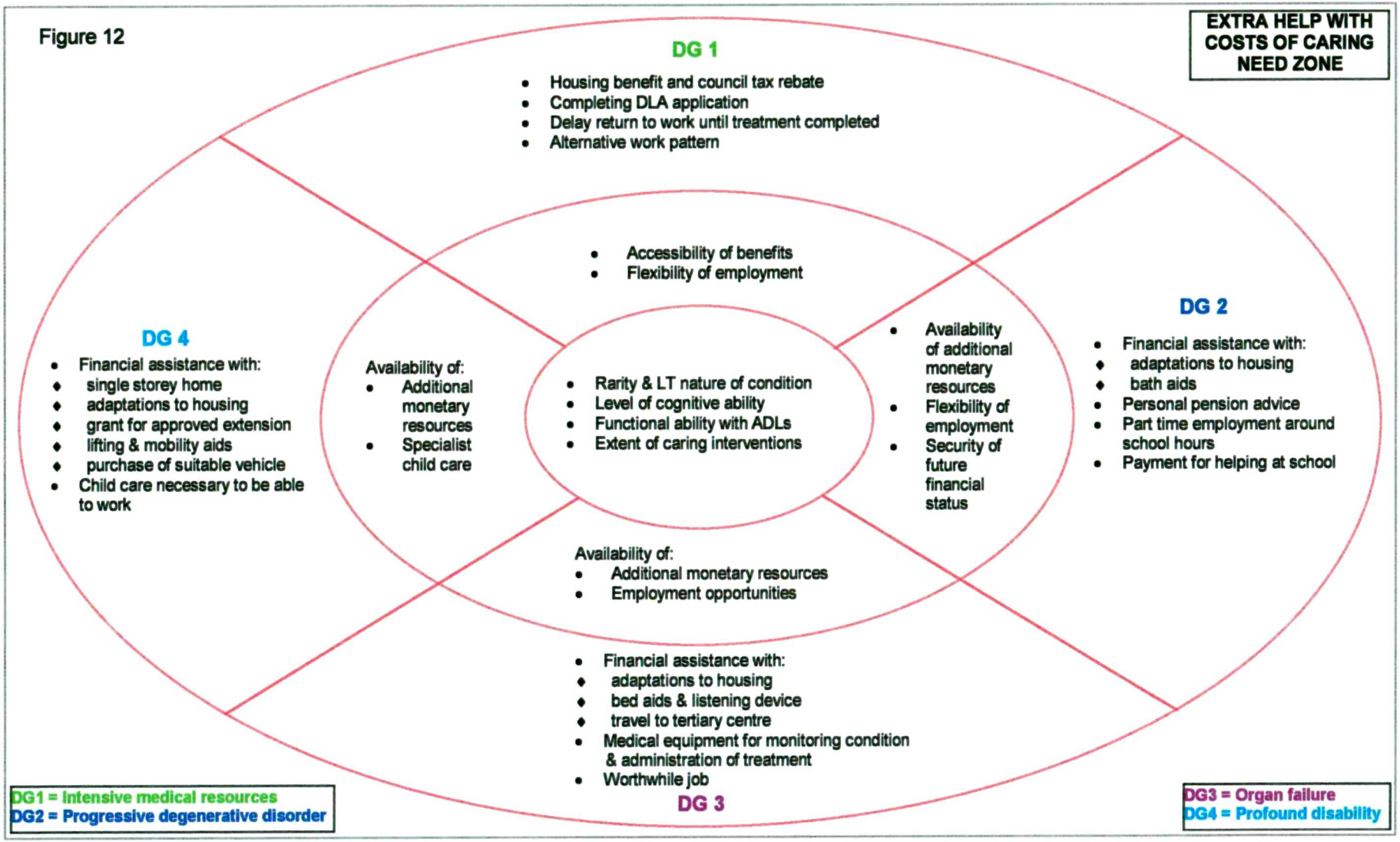
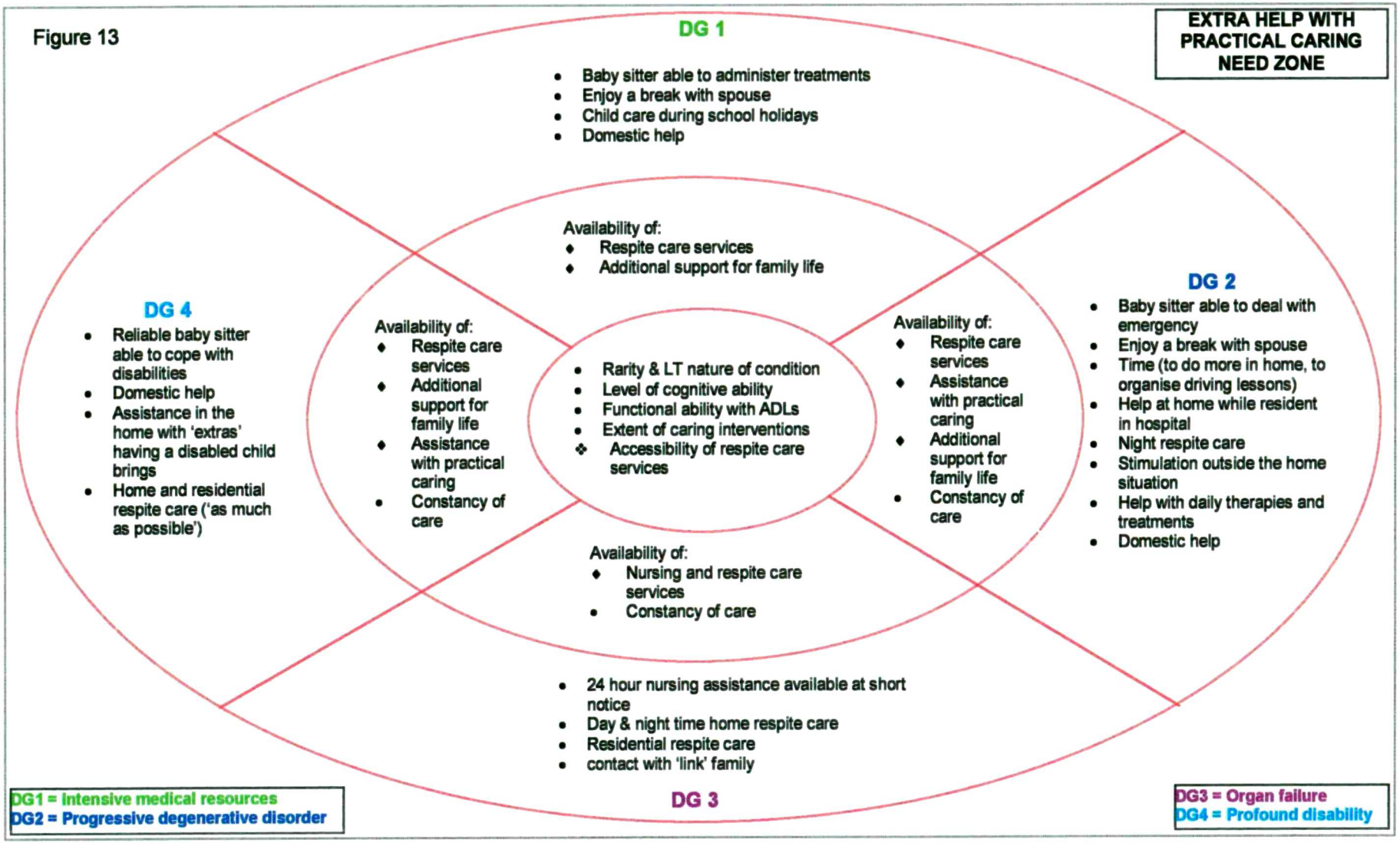

EXTRA HELP WITH COSTS OF CARING NEED ZONE
DG 1
Housing benefit and council tax rebate
Completing DLA application
Delay return to work until treatment completed
Alternative work pattern
Accessibility of benefits
Flexibility of employment
DG 4
Financial assistance with:
single storey home
adaptations to housing
grant for approved extension
lifting & mobility aids
purchase of suitable vehicle
Child care necessary to be able to work
Availability of:
Additional monetary resources
Specialist child care
Rarity & LT nature of condition
Level of cognitive ability
Functional ability with ADLs
Extent of caring interventions
Availability of additional monetary resources
Flexibility of employment
Security of future financial status
DG 2
Financial assistance with:
adaptations to housing
bath aids
Personal pension advice
Part time employment around school hours
Payment for helping at school
Availability of:
Additional monetary resources
Employment opportunities
Financial assistance with:
adaptations to housing
bed aids & listening device
travel to tertiary centre
Medical equipment for monitoring condition & administration of treatment
Worthwhile job
DG 3
DG1 = Intensive medical resources
DG2 = Progressive degenerative disorder
DG3 = Organ failure
DG4 = Profound disability

Figure 13


EXTRA HELP WITH PRACTICAL CARING NEED ZONE
DG 1
Baby sitter able to administer treatments
Enjoy a break with spouse
Child care during school holidays
Domestic help
Availability of:
Respite care services
Additional support for family life
DG 4
Reliable baby sitter able to cope with disabilities
Domestic help
Assistance in the home with 'extras' having a disabled child brings
Home and residential respite care ('as much as possible')
Availability of:
Respite care services
Additional support for family life
Assistance with practical caring
Constancy of care
Rarity & LT nature of condition
Level of cognitive ability
Functional ability with ADLs
Extent of caring interventions
Accessibility of respite care services
Availability of:
Respite care services
Assistance with practical caring
Additional support for family life
Constancy of care
DG 2
Baby sitter able to deal with emergency
Enjoy a break with spouse
Time (to do more in home, to organise driving lessons)
Help at home while resident in hospital
Night respite care
Stimulation outside the home situation
Help with daily therapies and treatments
Domestic help
Availability of:
Nursing and respite care services
Constancy of care
24 hour nursing assistance available at short notice
Day & night time home respite care
Residential respite care
contact with 'link' family
DG 3
DG1 = Intensive medical resources
DG2 = Progressive degenerative disorder
DG3 = Organ failure
DG4 = Profound disability

7.5.2.5 Information Need Zone (Figure 14)

The quality of information exchange between services and between professionals and the family was an important contributing factor likely to affect need and was common to all disorder groups (Box 6). In addition, the extent to which parents participated in their child's care and management also influenced their need for help and support. A lack of information prevented parents from being full participants in their child's care.

7.5.2.6 Equipment and Resources Need Zone (Figure 15)

Commonality among disorder groups with factors likely to influence need for help was most evident in the Equipment and Resources Need Zone (Box 7). The extent to which aids and equipment were available and accessible was a factor revealed in all disorder groups. The quality of care co-ordination regarding aids and equipment was revealed as a factor in three of the four groups (children with progressive degenerative disorders (DG2), organ failure (DG3) and profound disability (DG4). In addition, the extent to which the child's environment (school, home, travel) was suitable and met their needs was also demonstrated in these three groups.

7.6 Macro level of analysis of expressed need within the Need Zones

7.6.1 Introduction

Themes of expressed need common to all disorder groups are presented here by Need Zone. Higher range of abstraction themes have been reproduced from the individual disorder group Maps of Expressed Need (Figures 6-9) and Appendices 5-22 and checked to remove duplication. The disorder groups in which themes were originally identified are recorded in parentheses. These themes contribute to the Map of Expressed Need (Figure 16).

Figure 14

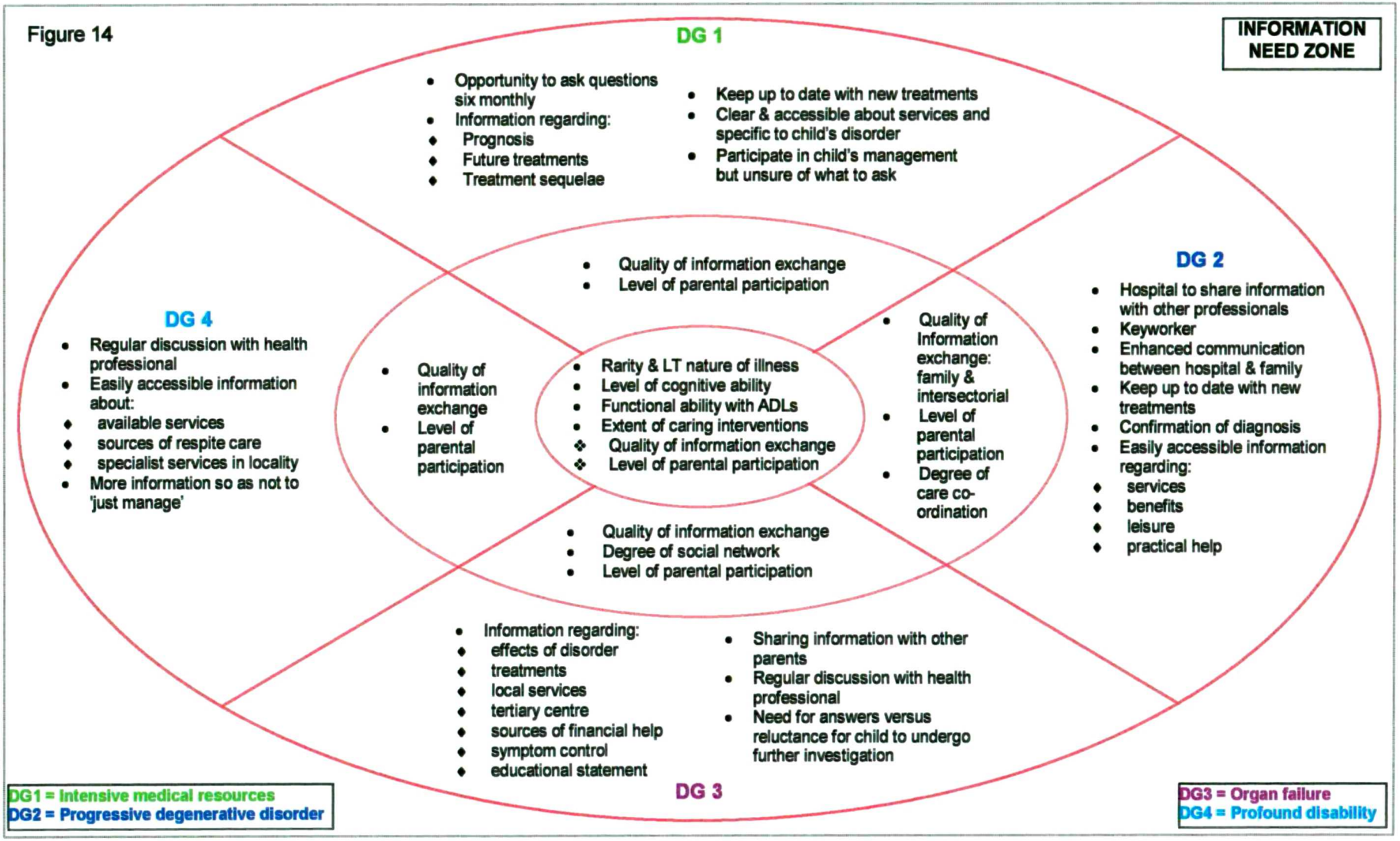
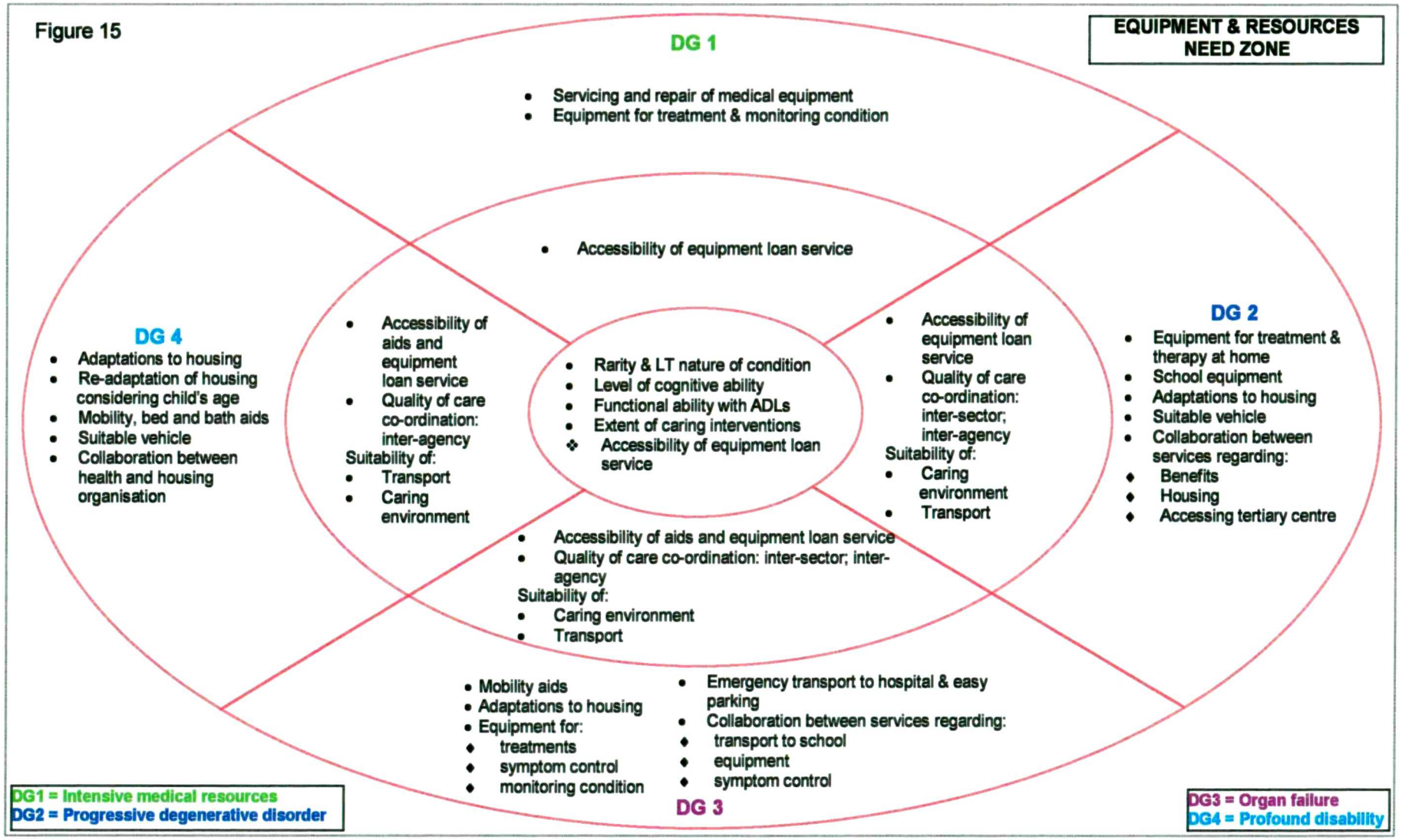
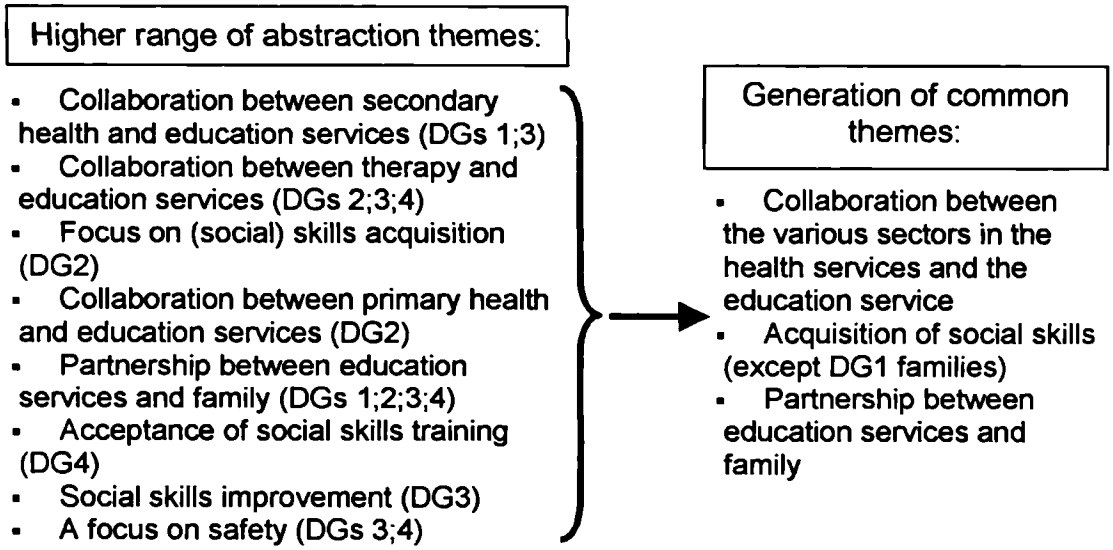

INFORMATION NEED ZONE
DG 1
Opportunity to ask questions six monthly
Information regarding:
Prognosis
Future treatments
Treatment sequelae
Keep up to date with new treatments
Clear & accessible about services and specific to child's disorder
Participate in child's management but unsure of what to ask
DG 2
Hospital to share information with other professionals
Keyworker
Enhanced communication between hospital & family
Keep up to date with new treatments
Confirmation of diagnosis
Easily accessible information regarding:
services
benefits
leisure
practical help
DG 3
Information regarding:
effects of disorder
treatments
local services
tertiary centre
sources of financial help
symptom control
educational statement
Sharing information with other parents
Regular discussion with health professional
Need for answers versus reluctance for child to undergo further investigation
DG 4
Regular discussion with health professional
Easily accessible information about:
available services
sources of respite care
specialist services in locality
More information so as not to 'just manage'
Quality of information exchange
Level of parental participation
Quality of information exchange
Level of parental participation
Quality of information exchange
Degree of social network
Level of parental participation
Quality of Information exchange: family & intersectorial
Level of parental participation
Degree of care co-ordination
Rarity & LT nature of illness
Level of cognitive ability
Functional ability with ADLs
Extent of caring interventions
Quality of information exchange
Level of parental participation
DG1 = Intensive medical resources
DG2 = Progressive degenerative disorder
DG3 = Organ failure
DG4 = Profound disability

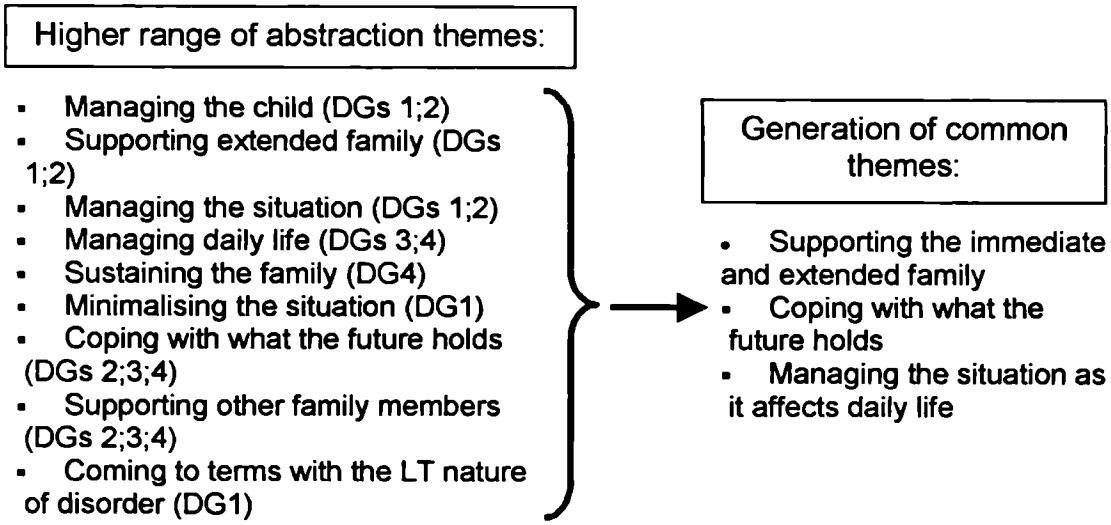
Figure 15


EQUIPMENT & RESOURCES NEED ZONE
DG 1
• Servicing and repair of medical equipment
• Equipment for treatment & monitoring condition
• Accessibility of equipment loan service
DG 4
• Adaptations to housing
• Re-adaptation of housing considering child's age
• Mobility, bed and bath aids
• Suitable vehicle
• Collaboration between health and housing organisation
• Accessibility of aids and equipment loan service
• Quality of care co-ordination: inter-agency
Suitability of:
• Transport
• Caring environment
• Rarity & LT nature of condition
• Level of cognitive ability
• Functional ability with ADLs
• Extent of caring interventions
❖ Accessibility of equipment loan service
• Accessibility of equipment loan service
• Quality of care co-ordination: inter-sector; inter-agency
Suitability of:
• Caring environment
• Transport
DG 2
• Equipment for treatment & therapy at home
• School equipment
• Adaptations to housing
• Suitable vehicle
• Collaboration between services regarding:
♦ Benefits
♦ Housing
♦ Accessing tertiary centre
• Accessibility of aids and equipment loan service
• Quality of care co-ordination: inter-sector; inter-agency
Suitability of:
• Caring environment
• Transport
• Mobility aids
• Adaptations to housing
• Equipment for:
♦ treatments
♦ symptom control
♦ monitoring condition
• Emergency transport to hospital & easy parking
• Collaboration between services regarding:
♦ transport to school
♦ equipment
♦ symptom control
DG 3
DG1 = Intensive medical resources
DG2 = Progressive degenerative disorder
DG3 = Organ failure
DG4 = Profound disability

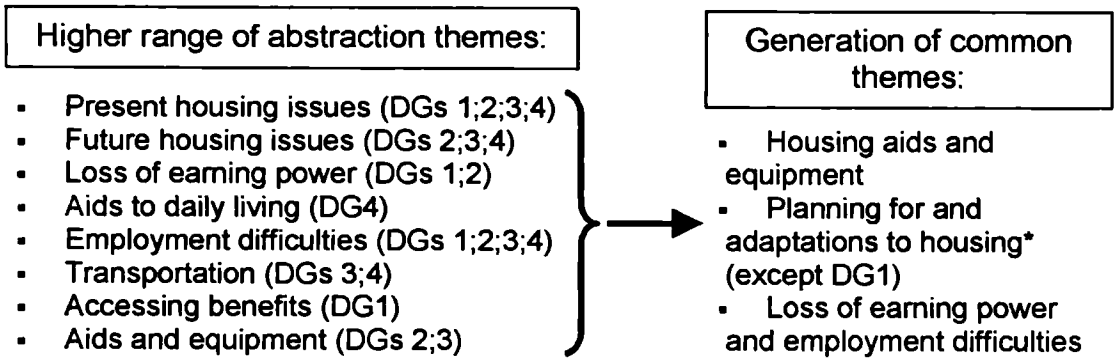
7.6.2 Intersectorial Working Need Zone



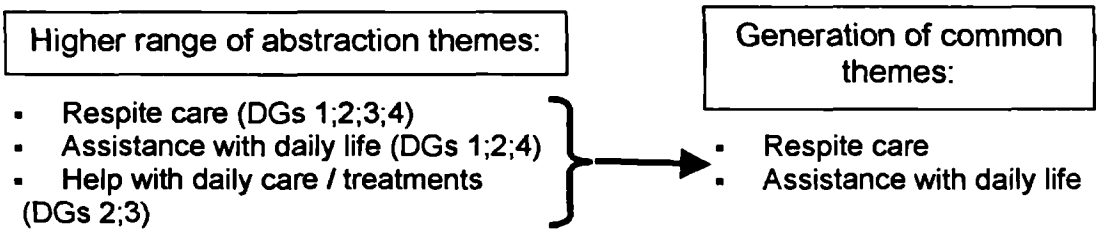
7.6.3 Coping Strategies and Resources Need Zone



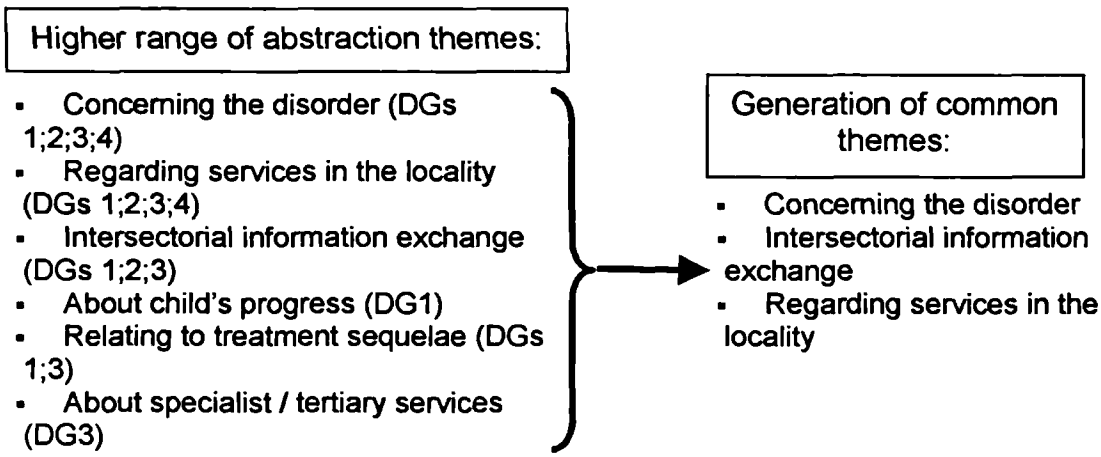
7.6.4 Extra Help with Costs of Caring Need Zone



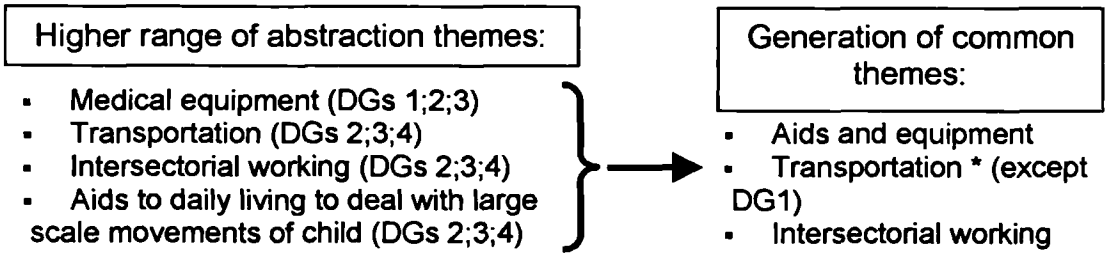
7.6.5 Extra Help with Practical Caring Need Zone



7.6.6 Information Need Zone



7.6.7 Equipment and Resources Need Zone



7.7 Development of Map of Family Need

7.7.1 Introduction

The Map of Family Need (Figure 16) offers a macro view of the expressed needs of families caring for a child with a LTI. It comprises two main levels. The inner ellipse divided into six segments is made up of the Need Zones descriptors (core themes). The outer level contains those higher range of

abstraction themes which are common to all disorder groups in each of the Need Zones. The Coping Strategies and Resources Need Zone has been chosen as an exemplar to illuminate how the expressed needs of families at a more specific (less abstract) level are unique to each disorder group.

7.7.2 Map of Family Need: commentary

The principal common theme among all disorder groups within the Intersectorial Working Need Zone concerned the need for a collaborative working approach between primary and secondary health service professionals and those (teachers, learning support assistants and ancillary staff) working in the child's school environment. An additional theme revealed the need for teachers to adopt a partnership approach with the family. Families of children with some form of learning disability identified a need for their child to acquire an acceptable level of social skills. This was not revealed by families of children requiring intensive medical resources (DG1). None of the children in this disorder group had a statement of special educational need in place and thus were unlikely to have been identified as having substantial learning difficulties. Social skills were perceived as important when academic attainment was likely to be limited.

The main theme in the Coping Strategies and Resources Need Zone common to all disorder groups concerned the need for coping strategies and resources to help the respondents (i.e. principal carers who were mothers in all but one case) support members of their immediate and extended family. The need for strategies and resources to cope with the future situation (i.e. the deterioration of their child's health and / or the death of their child) or potential LT situation (for families of children requiring intensive medical resources (DG1)) was common to all groups. The need for help with managing the situation and their daily lives was also revealed across the disorder groups.

The need for additional financial help with housing adaptations, aids to daily living and equipment were situations common to all the disorder groups with

the exception of families of children requiring intensive medical resources (DG1). The functional ability of children in this disorder group was not affected and thus they did not demonstrate the need for changes to their accommodation. Concerns regarding their present housing situation were revealed in DG1 however, and pertained to the need for assistance with housing payments caused by loss of earning power. This and other employment difficulties attributable to the child's illness were also common to all other disorder groups. Unlike the other three groups, the need for help with additional costs of caring was not identified with children requiring intensive medical resources (DG1). This was likely due to the nature of the illnesses comprising this disorder group where the costs of caring (e.g. drug treatments) were borne by the health services.

Unsurprisingly, the principal common themes within the Information Need Zone were revealed as the need for help with information about the child's disorder and for information concerning the availability of services near to the family home. The need for intersectorial information exchange was also illuminated by families of children requiring intensive medical resources (DG1), progressive degenerative disorders (DG2), and organ failure (DG3) and was implicit in themes generated by families of children with profound disability (DG4). The lack of an explicit expression of need for information exchange between the different service sectors by families in this disorder group (DG4) was noteworthy, as children in this disorder group had very poor functional and cognitive ability and their families reported contact with a large number of different professionals. One possible reason for this was that these children were already well established within the different services, in particular in the health services and at school. In addition, the Children's Disability Team (which comprised workers from health and SSDs) offered a unique service to this disorder group.

The dominant common theme in the Equipment and Resources Need Zone concerned the need for additional practical help with obtaining medical equipment and aids to daily living. Difficulties associated with acquiring suitable aids and equipment called for a collaborative working approach

between the different services involved with families. This theme was explicit in the groups of children with progressive degenerative disorders (DG2), organ failure (DG3) and profound disability (DG4) and implied by families of children requiring intensive medical resources (DG1). Transportation issues concerning the need for an appropriate vehicle to mobilise the child and family were revealed in all disorder groups except for families of children requiring intensive medical resources (DG1). The lack of expressed need with transportation issues for DG1 was because children in this group did not have physical disabilities which necessitated special modes of transport. The DGH / tertiary centre was very local to the study area, thus few families expressed a need for assistance with access to hospital.

Not unexpectedly, the common themes revealed in the Extra Help with Practical Caring Need Zone concerned the need for some relief from the additional caring tasks undertaken by families which exceeded normal parenting responsibilities. Obtaining respite care in and out of the home environment and assistance with daily care and treatments in the home were also recognised across all four disorder groups.

Factors likely to influence family need are displayed in three sections.
1) Structural constraints in which families lived out their lives were outside the scope of professional CCN practice:

- place and type of accommodation
- social support structure
- presence of second affected child
- presence of healthy siblings

2) Factors which were common to all disorder groups but specific to the appropriate Need Zone:

- external coping resources (Coping Strategies and Resources)
- additional monetary resources (Extra Help with Costs of Caring)
- access to respite care (Extra Help with Practical Caring)
- quality of information exchange (Information)
- level of parental participation (Information)
- equipment loan service (Equipment and Resources)

FACTORS AFFECTING NEED

- ❖ Rarity & LT nature of disorder
- ❖ Functional ability of child with ADLs
- ❖ Level of cognitive ability of child
- ❖ Extent of caring interventions

- ▪ External coping resources
- ▪ Additional monetary resources
- ▪ Access to respite care
- ▪ Information exchange
- ▪ Parental participation
- ▪ Equipment loan service

- ◆ Second affected child
- ◆ Healthy siblings
- ◆ Place & type of accommodation
- ◆ Social support structure

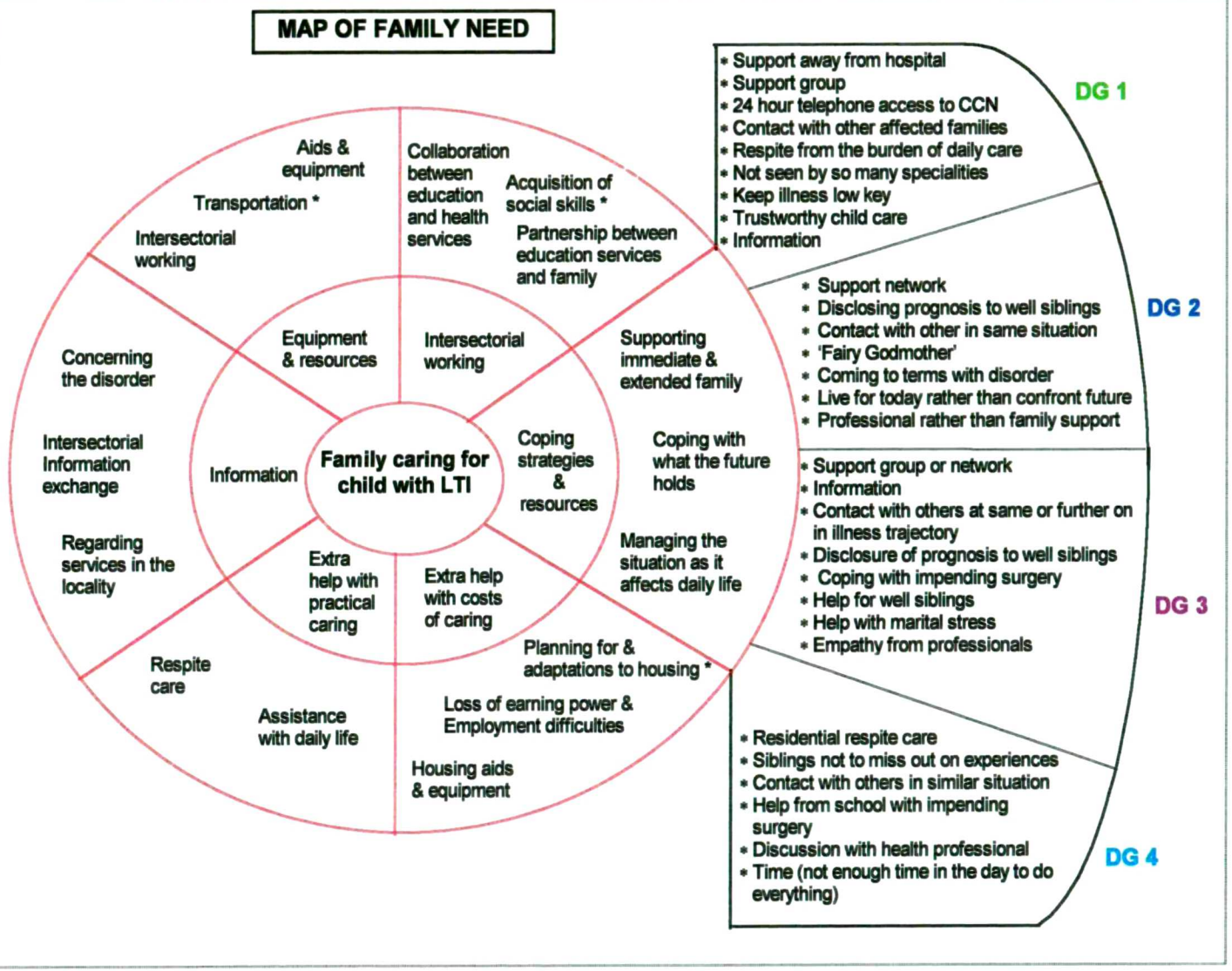


Figure 16

* = Except DG 1

3) Factors which were common to all disorder groups across all Need Zones:

- rarity and life-threatening nature of the disorder
- functional ability of child with activities of daily living
- cognitive ability of child
- extent of caring interventions undertaken by parents

7.8 Summary

Themes on mezzo and macro levels were derived from the micro level of analysis themes revealed in Chapter 6. Models for the six Need Zones were developed which explored the relationship between expressed need and factors likely to affect families need for additional help. Commonality and diversity among the four disorder groups were revealed in the mezzo level of analysis of children's functional ability, caring interventions performed by parents and factors likely to influence the expressed needs of families. The generation of themes common to all disorder groups derived on a macro level was consistent with a non-categorical approach. Families of children with LTIs, regardless of diagnosis, expressed a range of needs across all six Need Zones and a number of factors were likely to contribute to the level of need expressed by families. Exploration of factors which might influence a family's need for additional help warrants further research so that predictors of family need may be developed. Themes on a macro level are diagrammatically represented in the Map of Family need (Figure 16).

Chapter 8 Discussion

8.1 Introduction

It is now commonplace for families of children with LTIs to manage the complexities of their child's care within their own homes. This study revealed that the continuing care demands of children with such illnesses were substantial. In addition, it demonstrated that families caring for their children at home required help and support from a variety of services to enable them to be effective in their caring role. Despite recent policy changes within health, education and social services for sick and disabled children (Children Act, 1989; NHS and Community Care Act, 1990; Education Act, 1993; Carers Act, 1995) and the recommendations of many government reports concerning the expansion of home care services for children (Ministry of Health, 1959; Department of Health and Social Security, 1976; Department of Health, 1991; NHS Executive, 1996; NHS Executive, 1998), families frequently have unmet needs and find themselves unsupported in their caring role.

The findings from this study echo those of other research namely the need for information (e.g. Quine & Pahl, 1989; Sloper & Turner, 1992; Beresford, 1995), more practical support with caring interventions in the home (e.g. Stein & Woolley, 1990; Soutter et al, 1994; While et al, 1996a), obtaining some relief from the 24 hour responsibility of care (Beresford, 1995), the psycho-social effects experienced by all family members (e.g. Burton, 1975; Whyte, 1992; Havermans & Eiser, 1994), coping resources and strategies (Sloper & Turner, 1992; Beresford, 1995), and the additional financial implications of caring for such a child (Bodkin et al, 1982; Smyth & Robus, 1989; Stein & Woolley, 1990; While et al, 1996a).

A significant reduction in the number of expressed informational, practical and social needs of families at the final interviews was revealed by families who received nurse-led interventions. Several explanations may account for the significant changes in family need. The researcher may have brought

about change through intervening with practical help and support, although changes in a child's health status may have influenced the level of need expressed. The study design meant that families' experiences had evolved during the year of data collection. Also during this period changes and developments in service provision outside the influence of the study may have had an effect on family need. Furthermore, it is possible that knowledge of the study and anticipation of enhanced services may have influenced families' responses, with participants reporting less need at the final interview to please the researcher.

Despite these possible explanations it is clear that the level of expressed need was reduced significantly in intervention group families during the period in which the principal change in service provision for them was the introduction of nurse-led interventions. A relationship was established quickly between the researcher and the family where problems could be discussed and solutions sought. This might in part be due to the researcher's prior nursing experience but also to the fact that relationships were formed within the family home without the barriers which may be present in the hospital environment. The development of the relationship in the family's own environment likely contributed to the quality of the partnership relationship and is consistent with the views of Lessing and Tatman (1991).

Analysis of key aspects of the CCN role revealed that the researcher demonstrated a variety of professional skills and qualities to provide an effective and quality service to families and these formed the basis of the model for Community Children's Nursing (Figure 17). This model should be particularly relevant to 'Diana Nursing Teams' which are presently defining their client group and role and determining how best to evaluate the effectiveness of their services.

8.2 The sample families

The lack of a comprehensive morbidity database posed difficulties in the recruitment of families and led to the lengthy process in which health professionals were asked to nominate families whom they thought might be

suitable. More than half the children nominated did not meet the study criteria. General practitioners were one and a half times more successful than SNs and almost twice as successful as HVs in identifying children consistent with the criteria. This might suggest that the basis for the operational definition reflected the medical model rather than the nursing model. The large number of children who did not meet the criteria may have meant that the operational definition was misunderstood. But more likely, it may have been a true reflection of the number of families caring for children with major health problems who had needs which were not being met.

It is clear that there is an urgent need to record accurately the number of live children with LTI on some form of morbidity data base either at district, regional or national level using a common data set. While et al (1996a) described three national disorder registers which record the number of children living with cancer, cystic fibrosis and mucopolysaccharidoses. A more appropriate method might be a register maintained at local level which includes information concerning the status and needs of all families caring for a child with a LTI (Wallace & Jackson, 1995). This might offer a useful contribution to strategic and service planning for both purchasers and providers in the area.

A degree of sample loss at recruitment related to direct family refusal (n=10, 11.6%) was expected. There were other admissible reasons for attrition such as the death of a child, movement away from the area, successful surgical intervention, or incorrect allocation to the sampling frame. However, what was unforeseen and outside the researcher's control was the extent to which nominating health professionals (n=9) declined to approach the families whom they had nominated during the nomination survey. Thus, families were prevented from having the opportunity to decide for themselves whether they wanted to participate. Health professionals either perceived themselves to be acting in the best interests of the family, i.e. protecting them from additional stress from contact with another professional, or felt that they were helping the researcher by preventing her from spending time and resources on families whom they knew would not wish to participate.

As the sample was small, stratification and randomisation by age and gender was not undertaken. Despite this an even distribution across the age ranges was demonstrated in both intervention and control groups with boys and girls being equally represented when the sample was considered as whole. The majority of families in both groups were from socio-ecomonic group II which is likely to reflect the relative affluence of the geographical area in which the study took place (an English university city). The low representation of lone parent families in this study (n=1) compared with those in other studies (21% Sloper & Turner, 1992; 25% Beresford,1995; 18.2% While et al, 1996a) and the extent to which families were home owners (73.6%), the vast majority of who were situated in villages outside the city boundary, were further examples of the relative wealth of the study area which is within commuting distance of London.

A large number of families reported that their child's LTI had led to restrictions in normal social activities. For example, two fifths of families felt that taking a holiday in England was difficult, while just under a third felt that going out for the day as a family was problematic. This probably related to the lack of functional ability and the consequent care demands of a large minority of children. The most frequently reported problems regarding age appropriate difficulties with ADLs for more than half the sample were: continence, dressing, washing and bathing. More than a third of families reported that their child had difficulty with eating and drinking, with a quarter experiencing problems with communication and behaviour.

Parents performed many caring interventions for their child which depended upon the treatment demands of the illness itself. Similar to families in While et al's (1996a) study, families undertook complicated procedures such as tracheo-pharyngeal suction, the administration of intravenous, subcutaneous and per rectum medications, both regularly and in an emergency situation. The most frequently reported caring intervention was the administration of medicines. This contrasts with While et al's (1996a) findings which revealed that physiotherapy was the most frequent intervention undertaken for their sample. This may have been due to the large number of children with CF in

their study sample.

8.3 Quantitative findings

The main findings from the quasi-experimental component of the study were:

a) At recruitment all families in the intervention group expressed a need for more help with caring for their child(ren) and on average reported 5.2 items of need.

b) At the final interview the intervention group families reported significantly fewer needs (2.8 needs).

c) There was a significant difference between the number of needs in the informational, practical and social need domains expressed by intervention group families at recruitment and final interviews.

d) At recruitment families expressed most need for additional help with items in the informational need domain.

e) The items of greatest need in each of the six domains were:

Information about available services; a link between hospital and home; skilled child minding; difficulties with other family members and an informal support network; special educational facilities and measures to improve housing.

f) Findings from the CHIP questionnaire revealed that a third of intervention group mothers obtained scores outside the normative range for strategies concerned with social support and communication with medical personnel.

A number of explanations may account for the significant changes in family need between the series of interviews with the intervention group. The simplest explanation is that the researcher in her clinical role as CCN, acting as a key worker, brought about change through intervening with practical help and support. From a nursing perspective it would have been a matter of concern if significant differences in family need in the informational, practical and social need domains had not been demonstrated, as these are areas

which should be influenced by effective family-centred nursing care (Jolly, 1981). Substantial liaison took place (in conjunction with the family) with professionals in health, educational and social services to access the most appropriate help for the participating families. Training and support specific to individual children was given to professionals and other staff to provide a safe environment for the child and, where possible, alleviate family and professional stress.

There are, however, other possible explanations for the significant differences expressed in family need. For the majority of children, their illness was not static during the year and both improvements and deterioration in their conditions were noted during the study period. Several children with chronic degenerative conditions experienced episodes of acute illness which were resolved with limited medical input. Other children required periodic intensive medical or surgical treatment and these were times of potential and actual crisis for the family. Changes in their child's health status may have influenced the family's level of need at the interview times.

Each family's natural history is another possible reason why differences have been demonstrated. For example, at the time of the final interview each family was a year further in their experience with the illness or the disability, with developing coping strategies and accessing helpful and supportive resources to assist them in their situation. Other life events, for example, the loss of an elderly family member, moving home or the child changing schools, may have also influenced how a family felt as they were being interviewed.

There were changes and developments in health, social services and LEA provision outside the influence of the study which may have had an effect on the family's level of need. For example, an increase in the social services contribution to the Children's Disability Team (Figure 5) may have led to the reduction in family need seen within the social and emotional need domains for those families receiving care from this service.

Finally, the 'Hawthorne' effect (Mayo, 1949) may be partly responsible for the

differences seen since families agreed to join the project and were interviewed several times. Their knowledge of the study and their anticipation of enhanced services may have influenced their responses. Families were also aware of the aim of the study: to provide evidence of the effectiveness of the CCN service, thus they may have reported less need at the final interview to influence the results, a phenomenon noted by Beresford et al (1996) where participants wish to please the researcher.

Two possible reasons to account for the absence of significant differences between pairs of interviews in the emotional need domain are the enduring stigma associated with the illness or disability and the potential for the loss of the child. These are constant factors which influence a family's requirement for emotional help (Meltzer et al, 1989). No significant differences were seen in the level of need for additional help in the educational and financial domains between the interview periods. For some families needs within these domains were interrelated. While training and support was offered and taken up by school staff for a variety of 'practical' health care tasks it was not possible to resolve some of the other problems identified by families, such as funding for additional learning support time for individual children.

8.4 Micro, mezzo and macro levels of qualitative data analysis

The process of analysis of qualitative data progressed naturally starting with the micro level of analysis and generation of middle range themes from the summation of expressed need from the verbatim quotations of families. There were a number of important factors pertaining to the micro level of analysis. Firstly, it was closest to the information given by the respondents and therefore should be of prime interest to those who deliver services to children and their families. Secondly, comparison between disorder groups at this level demonstrated a uniqueness among families comprising each disorder group and thirdly, findings on mezzo and macro levels emerged from this level of analysis.

These factors raised a number of implications for service providers. Firstly, difficulties associated with a non-categorical approach to assessing and

responding to the needs of families proposed by Stein and Jessop (1982) were illustrated. At the micro level (i.e. at family level), this study revealed the four disorder groups to be quite distinct from one another. Although some expressed needs within each Need Zone were common, the combinations of expressed needs differed. Highly specific needs which predominately related to the type of disorder and the care or treatment were revealed. Therefore, these findings do not support the use of a non-categorical approach for service delivery. Secondly, this level of analysis is particularly relevant to those providing care as it enhances knowledge of the needs of families. Such a knowledge base confers greater understanding and enhances the ability to develop a partnership relationship with families to support them in their caring role. Thirdly, such an understanding of the family situation should enable the anticipation of family need (proactive rather than reactive approach to service delivery) which is likely to prevent needs from arising and may also reduce the extent of Constancy of need. However, controlled evaluative studies are required to examine whether this is indeed the case. The four disorder groups Maps of Expressed Need (Figures 6-9) offer a comprehensive view of this level of analysis.

Findings on a mezzo level of analysis offer an intermediate step between micro and macro analyses of need. Emerging themes revealed specificity in family need but some commonality among the four disorder groups was also evident. Thus, this intermediate level of analysis is unlikely to be useful to disease specific or non-categorical approaches to the provision of care. However, this level was important as it provided a bridge from micro to macro levels of analysis. It enabled commonalities within the Need Zones in each of the disorder groups to be identified and provided the basis for a macro view of the expressed needs of families to be developed. In other words, this level facilitated the leap between family and organisation which is not often clearly defined.

The macro level of analysis of themes within each of the Need Zones revealed themes common to all disorder groups. The rarity of childhood LTI means that there are relatively few children with LTI in any one locality

(NAHA, 1988; While et al, 1996a). This makes it neither practical nor economical for service provision to be implemented at anything other than at this macro level. Community nursing services for children with LTIs are generally designed and implemented at this level and predominantly non-categorical in their approach (Stein & Jessop, 1982). It is extremely important for those working within this macro framework to be able to deliver services at a micro level i.e. as near to the child and family as possible. Sensitivity to the diverse needs of families and to the differing factors which may influence the needs of families caring for children with a variety of disorders is essential. Services which are not sensitive to these differences are unlikely to meet fully the needs of the families whom they serve.

This study confirmed Eiser's (1993) assertion that it is difficult to distinguish between the benefits of a non-categorical approach and one which emphasises that the unique qualities of particular disorders require specific interventions. On the one hand, at micro level, data showed that the disorder groups were unique. On the other hand, themes generated on a mezzo level revealed some commonality among disorder groups with complete commonality being identified during the macro level of analysis. Analysis of interventions revealed that a key aspect of the role of the researcher was the ability to deliver family-centred care at a micro level (i.e. specific to the needs of individual families) while working within the constraints of an organisation which provided a service on a macro level (i.e. from a non-categorical framework).

8.5 The six Need Zones

8.5.1 Intersectorial Working Need Zone

One of the principal normalising factors for children with LTIs is to go to school (Simons, 1994). However long or short their life may be children have the right to the opportunity to develop their potential abilities and enjoy the enrichment which education affords. Few studies have focused solely on the relationship between children with LTIs and education services. Findings from this study were overwhelming in the identification of a need for a

collaborative working approach between the various health care providers and education services to meet the expressed needs of families. The mezzo level of analysis of expressed need data in the educational need domain revealed the core theme common to all disorder groups was that of multi- and single sector intersectorial working. Almost one quarter of families in the intervention group expressed the need for a link between acute health services and their child's school at recruitment. One third of families expressed a need for special educational facilities or opportunities for their child, thus confirming that the provision of education for children with LTIs should not be considered a fruitless task (Jeffrey, 1990). A large minority of children had been assessed by the LEA and had a formal written statement of special educational need in place. Less than one quarter (23.5%) of children over five years of age attended one of the four special schools in the study area, while a minority of children in main-stream education had been through the 'statementing' process. This indicated a positive trend in the integration of children with special needs into the main-stream education environment.

Analysis of expressed need in this Intersectorial Working Need Zone revealed both differences and commonalities among the four disorder groups. Differences were due in part to the level of cognitive ability of the children in the different groups. None of the children requiring intensive medical resources (DG1) had a statement of special educational need in place and all were being educated in a main-steam environment, whereas all children with profound disabilities (DG4) had had their educational needs assessed. These children had been matched to special school provision which it had been determined would best be able to meet their needs (Lavelle, 1994). The need for training of school staff to be competent to undertake practical caring interventions was peculiar to children requiring intensive medical resources (DG1). Thus, the degree of competency of staff able to undertake these tasks was a factor which affected a family's level of need. Parents in this study had to liaise directly with school staff and many revealed that their child's situation was not taken seriously or they were perceived as over-anxious or over-protective and parallels the findings

reported by Vickers et al (1997).

Poor communication processes with school staff caused anxiety for parents. Respondents expressed the need for a partnership approach to facilitate information exchange between both parties. Parental need to inform the school about treatments sometimes conflicted with their desire for their child not to be singled out as different from his / her peers and was seen in children requiring intensive medical resources (DG1) and children with organ failure (DG3). This is consistent with observations noted by Eiser (1993).

This research confirmed the shift in emphasis from special to main-stream education for children with special educational needs (NHS Executive, 1996) with only the seriously cognitively impaired children in this study placed within the special school environment. Thus, it is a reality that main-stream teachers are faced more frequently with LTI and terminally ill children and therefore it is important that deficits in their professional training be rectified. Issues such as information about common childhood illnesses, the effects of illness on children's learning and about working with the parents of sick and disabled children (Closs & Burnett, 1995) should be included in their training curricula and would likely facilitate a partnership approach for which families expressed a need.

Qualitative data analysis demonstrated that children with LTIs can thrive in the main-stream school environment and that collaboration among health and education services professionals, coupled with the presence of a CCN can reduce parental need. Although, matched pairs analysis of intervention group mean need scores for the educational need domain (from which most of the Intersectorial Working Need Zone originated) did not reveal any significant differences between the series of interviews. These findings parallel those of Vickers et al (1997) in that close liaison between clinicians, schools, families and those involved in policy generation is essential. The role of the health services is important in reducing parental and professional anxiety, although services provided by medical and nursing staff in schools need systematic evaluation, a recommendation which has also been made by the NHS Executive (1996).

The need for a collaborative working approach was revealed throughout the study period by families of children with progressive degenerative disorders (DG2). Analysis of the serial data from the three interviews revealed a Constancy of need for a variety of help from therapists at school for this disorder group and was also identified on one or more occasion in the groups of children with organ failure (DG3) and profound disability (DG4). Thus the extent of availability of specialist therapists to practice within the school environment was revealed as a factor which was likely to influence family need. All children with progressive degenerative disorders (DG2) were in main-stream education but their families needed advice and help with facilitating the process of adapting this school environment. They expressed the need for therapists, such as physiotherapists and occupational therapists, to be involved in the planning process to make sure that adaptations were appropriate and then to ensure that they were actually carried out. There is a need, therefore, for a shift in the emphasis of the role of therapy services to encompass not only children in special schools but also to the needs of those in the main-stream environment as families found it stressful negotiating with health and LEA professionals. Beresford's (1994) study went further to reveal that dissatisfaction with an educational placement actually caused conflict with professionals and was distressing and exhausting for parents.

The extent of Constancy of need within the Intersectorial Working Need Zone was not revealed in any other Need Zone and this was further evidence for the need for a recognition of joint responsibilities and for a multi-professional service approach. Lavelle (1994) recommended that a realistic assessment of a child's needs can only be made when medical, social and educational information is shared by the professionals involved. Teachers have a unique part to play in enabling the child with a LTI to enjoy school and for education to act as a marker of a dying child's existence and significance. The CCN's or health professional's contribution is to ensure that teachers have all the information which they need regarding the illness and its effects. All professionals in contact with the child and family have a duty to work together to reduce family distress and anxiety wherever possible. Although, as evidence from the emotional need domain showed, a family's emotional

needs were unlikely to be met completely as uncertainty and the threat of death were always present.

Some families of children with degenerative disorders (DG2) in main-stream education were concerned with the lack of their child's academic progress and this mirrored Closs and Burnetts's (1995) findings. For the child with a degenerative disorder education can offer an opportunity for them to thrive intellectually despite physical limitations. For some, schooling can be viewed as a distraction from distressing treatments and repetitive therapies. Such difficulties arising for families in this study may have been due to teachers' lack of experience of LTI in their personal lives (Eiser, 1993) or deficits in teachers' professional training (Closs & Burnett, 1995). Therefore, one component of the role of health professionals and in particular the CCN is to share information with school professionals about common disorders, effects of treatments and prognoses or to dispel negative expectations or inappropriately positive views of the LTI.

Families of children with profound disabilities (DG4), all of whom attended a special school in the study area, had accepted their child's lack of academic potential. However, they were adamant in their need for their child to be able to participate in activities which their child enjoyed such as horse riding and swimming. A finding also revealed in Beresford's (1994) study where families who expressed satisfaction with their child's schooling did so because they perceived that others were interested in their child. For teachers to show interest fostered feelings of being supported in giving their child the best from life. This is additional evidence for the need for a partnership approach between school and home which was expressed by families in all disorder groups.

Families perceived shortfalls in staffing levels at special schools sometimes created an unsafe situation and therefore expressed a need for their child to be educated in a safe environment. Only two of the children with profound disabilities (DG4) had full time learning support assistants and both of these children had a tracheostomy. Those families whose child did not have a classroom assistant felt that their child's needs warranted such additional

support. This situation caused conflict between families and school staff, with one family removing their child from school temporarily following an incident. This increased greatly the burden of care on the family who viewed school as an acceptable means of obtaining some relief from the caring role which benefited both child and family, a finding also elucidated by Beresford (1994).

Seven factors affected the needs of families in the Intersectorial Working Need Zone (Figure 10) although none were common across all disorder groups. The quality of care co-ordination and the exchange of information both within and across organisational boundaries including the family home were the principal factors which influenced a family's level of need. This supports the need for a collaborative working approach among professionals and for professionals to adopt a partnership working approach with families and also verifies Lavelle's (1994) perspective.

8.5.2 Coping Strategies and Resources Need Zone

The process model proposed by Lazarus and Folkman (1984) is suited to the care of families of children with LTIs as its principal components are coping resources and coping strategies. These can be used to determine how a family assesses their situation and the circumstances in which they find themselves and also how stressful they consider their situation to be. Families also revealed their need for an array of coping strategies and such a model is also useful in identifying those strategies which can be developed and utilised to manage stressful situations. Furthermore, these can be used to extend knowledge and understanding of why some families cope better than others when faced with a similar set of circumstances (Davis, 1993; Eiser, 1994).

The extent of need reported by families within the emotional need domain was striking and confirmed that the main burden of caring for a child with a LTI was emotional (Burne et al, 1984; While et al, 1996a). A wide range of concerns pertaining to the need for coping strategies and resources were expressed by families in all four disorder groups and this finding echoes that

of several other studies (Stein & Woolley, 1990; Sloper & Turner, 1992; Baldwin & Carlisle, 1994; While et al, 1996a).

Childhood cancer has become a model for conducting psychological research for children with other LTIs (Eiser, 1994) and a model for service provision with facets such as multi-professional working and shared care (Evans, 1993). Despite these advances little evidence from this study revealed that families requiring intensive medical resources (DG1) expressed a need for fewer coping strategies and resources than families of children in the other disorder groups. Although, this may be due to the children with cancer (n=4) being a sub-set of the whole disorder group (DG1).

This study examined the continuing care needs of families neither at the beginning nor the end of their experiences with LTI. Nevertheless, families in all disorder groups revealed the need for strategies to come to terms with the illness and for helping other family members to understand the situation. Strategies and resources should thus be offered by services, particularly the CCN, to enable families to develop significant and meaningful sources of informal support. These can often be found in relationships with immediate and extended family members, a recommendation which echoes that of Peace et al (1992), and are likely to empower families in their caring role (Gibson, 1995).

The loneliness and isolation experienced by families of children with LTIs has been well documented (Lavery, 1990; Florian & Krulik, 1991; While et al, 1996a). Almost a quarter of families in the study reported that their child's illness caused them to feel isolated from their family and friends. Not unsurprisingly, this was mainly due to the time restrictions imposed by the caring demands of the more severely disabled children and was particularly evident in the profound disability group (DG4).

Respondents expressed the need for contact with similarly affected families to provide a forum for the exchange of information, help and support. Such informal forms of support have already been reported as a helpful resource in assisting parents to manage their situation (Eiser & Havermans, 1992) but is

reiterated because it is an important unmet need which still persists. Mothers with high socio-economic backgrounds, however, are less likely to take advantage of group support when such services are offered (Dale, 1996). The relative affluence of the study area and the high proportion of families from socio-economic groups I and II meant that the researcher and other professionals needed to find an alternative to the 'support' group as a means of putting families in touch with one other.

The need to minimise their situation and thus regain or maintain some normality in their daily lives was peculiar to families requiring intensive medical resources (DG1). While it is not unusual for families to strive for normality (Canam, 1993) and to minimise the impact of the illness on family life (Eiser, 1990) the type of disorder does influence the extent to which families strive for normalisation. Children requiring intensive medical resources (DG1) suffered with acquired disorders rather than those which were congenital or hereditary. Thus, by definition families had experienced normality prior to diagnosis. It is possible, therefore, that families in DG1 expressed a need to minimise their situation in order to regain 'a normality' which had been subsumed by the LTI.

Interestingly, families of children with degenerative disorders (DG2) did not express a need for additional help within the emotional need domain at recruitment, although needs were expressed in the other five domains. It is likely that families did have needs within this domain as all other groups reported emotional needs, however, for some reason respondents in DG2 did not express them. It is possible that families did not want to divulge personal information with the researcher whom they had just met and had not yet established a rapport, although this is unlikely as other disorder groups reported emotional needs and were also meeting the researcher for the first time. A more plausible explanation is that families in this disorder group (DG2) were overwhelmed with informational, practical, social, financial and educational needs which eclipsed their ability to articulate their need for coping strategies and resources. It is not uncommon for families to place the practical caring needs of their child first to the detriment of their own personal

needs (Goldman & Baum, 1994; Gravelle, 1997). This finding supports the study design and highlights the importance of undertaking a series of interviews over a period of time. Had only one interview taken place a substantial amount of expressed need would have gone unnoticed and have resulted in an incomplete picture of the situation.

During subsequent interviews families revealed the need for strategies to improve the management of their situation. Beresford et al (1996) have recognised this to be the focus of present research which has shifted away from measuring psychiatric disturbance in children and families (Eiser, 1994) to an emphasis on living with an illness. Thus, present research should inform interventions and practice by all professionals involved with a family and should centre on assisting the child and family to mimimise the effects on their daily lives.

Parental attitudes to life, their physical and mental health, personality traits as well as skills they already have in their possession are factors which influence how parents manage a problem or situation (Beresford et al, 1996). Thus, it is an important aspect of the professional's role to assess accurately the coping resources families have available to meet their emotional needs. Families in this study revealed the need for strategies to deal with a variety of aspects pertaining to their child's illness and their situation, for example, coming to terms with what was happening to their child, dealing with uncertainty and difficulties which would likely arise in the future as well as coping with the inevitable death of their child. These findings are similar to those revealed by Stein and Woolley (1990). The need to develop ways to help healthy siblings to understand the situation was also revealed and echoes findings from other studies which have shown that healthy siblings have an increased risk of experiencing emotional and behavioural problems (Martinson et al, 1990; Breyer et al, 1993; Williams, 1997). Although in-depth investigation of the effects on healthy siblings was beyond the remit of this study the fact that families expressed a need for assistance with developing strategies to help healthy siblings demonstrated that problems were experienced and thus an area warranting further research.

Unlike families of children with progressive degenerative disorders (DG2) where death in childhood or early adulthood is certain, families of children with organ failure (DG3) face a different set of problems. For these children curative treatment may be feasible but can be unsuccessful (Sutherland et al, 1993; ACT & RCPCH, 1997). Although technological and surgical advances have enhanced the life expectancy and improved prognoses for children with cardiac abnormalities for example (Joffe & Vergoda, 1990) the course of the illness is often unpredictable and means that the family must live with varying degrees of uncertainty. Few studies in the literature discuss the particular problems faced by families caring for children with disorders causing organ failure such as congenital heart disease (CHD) despite the fact that this problem is fairly common and affects 8:1,000 live births (Jordan & Scott, 1989). Although this figure relates to the whole spectrum of CHD this study revealed that families of children with complex CHD (a sub-set of children with organ failure (DG3)) frequently faced life-threatening events. Families of children in this disorder group revealed a Constancy of need for strategies to deal with future events, in particular the need for strategies to help them deal with impending LT surgery.

The provision or acquisition of information was perceived as an important coping resource by families in the study which enabled them to understand and make sense of what was happening and assist them in planning for the future. This mirrors findings of other studies, for example, Quine & Pahl (1989); Stein & Woolley (1990); Sloper & Turner (1992); Jerret (1994); Beresford (1995) and While et al (1996a). Such is the importance placed on receiving timely, appropriate and accurate written and verbal information that this area required its own Need Zone to outline the range and types of information required by families. Nevertheless, the need for information as a coping resource was demonstrated to enhance families' ability to develop their own personal coping strategies, and build up a body of practical knowledge and expertise (Beresford, 1994). Therefore, information is especially important as it is both used as a resource and for developing strategies.

The need for effective social support was expressed by families as a means by which to facilitate their coping processes and relationships with others. It was also important as a way of managing their own situation more effectively by being able to give and receive support by sharing information and experiences. Families expressed a need for both formal and informal sources of support. This finding is consistent with other studies (Brown & Hepple, 1989; Beresford, 1995; While et al, 1996a), and particularly with Gibson's (1995) exploration of the process of empowerment in mothers who clearly gained informal support from others in a similar situation. Further evidence was revealed in the analysis of the CHIP data in which a third of intervention group mothers scored outside the normative range for strategies concerned with social support. Providing families with the opportunity to belong to a support group is thus an important element of the professional's role in enabling families to cope, a finding also reported by Stein and Woolley (1990). Evidence from this study, however, showed that some families preferred contact on a one to one basis with a similarly affected family rather than in a group environment. Thus, another important aspect of the role of the professional is to be able to identify families in any one area who may be able to support each other. Additionally, professionals, in particular the CCN, should develop a partnership relationship with families so that forms of support may be discussed in such a way which does not breach patient and family confidentiality.

The formation of positive relationships with professionals, in particular with those from health services, enhances parents' ability to use them as a coping resource (Beresford, 1994). The need for more formal forms of support from statutory organisations was expressed by families in this study. Findings from the CHIP data showed that a third of intervention group mothers obtained scores below the normative range in the coping pattern concerned with communication with medical personnel. Families expressed the need for community health professionals to be equipped with skills to anticipate and respond to their needs. This finding suggested that relationships with professionals for some families were not based on a partnership approach.

The need for help with managing daily life was a prime theme which emerged from the Coping Strategies and Resources Need Zone particularly for families of children with profound disabilities (DG4). The need for more time in the day was particularly evident. Parents in this disorder group frequently described a rushed family life with not enough time for normal daily activities, a finding consistent with that of Duncan and O'Flynn (1995). A key aspect of the professionals' role is to enable families to manage their time more effectively and re-negotiate their daily activities with the provision of additional domestic or child care help in the home being available if necessary.

Respondents (predominately mothers) were reluctant to express a need for help with marital problems. Although evidence of need was implicit in some interviews and confirmed the findings of earlier studies which have shown that the strain on the marital relationship is considerable (Baldwin & Carlisle, 1994; Stein et al, 1989; While et al, 1996a). Parents expressed the need for some time alone with each other, an indication that their marital relationship was important, but their child's needs frequently took precedence. The practical demands and the emotional consequences of their caring role meant that parents had less time to spend together, a phenomenon further complicated by difficulties in finding a trustworthy babysitter able to deal with the child's extraordinary needs, an observation consistent with evidence proposed by Eiser (1990).

The need for respite care as a means of coping with their situation was expressed by families in all disorder groups but particularly by those of children with profound disabilities (DG4) who needed time to help healthy siblings participate in their own activities. This was one of three factors which influenced the needs of families in The Coping Strategies and Resources Need Zone (Figure 11) with the availability of external coping resources such as appropriate respite care common to all disorder groups. Stallard et al (1997) recommended that parents 'make' time to enjoy the normality of non-illness related life with their healthy children. Findings in this study revealed this to be difficult. One mother was required to 'train' health professionals in a

residential respite care establishment about aspects of her child's care so that her healthy daughter could 'get away' from the illness occasionally. The training process was both time consuming and laden with anxiety for this mother and further evidence that the caring burden on parents can be increased by well meaning but thoughtless professionals, a finding consistent with that of Sloper & Turner (1992).

8.5.3 Extra Help with Costs of Caring Need Zone

Unsurprisingly, refinement of the core theme generated from the financial need domain revealed a recurrent image across the disorder groups of the additional financial costs borne by families in their caring role. Measuring the extent of extra financial costs was problematic in this small scale study although more than two fifths of families in the intervention group at recruitment expressed the need for extra financial advice and for measures to improve their housing. These findings are consistent with the national OPCS survey of disability which revealed that families incur additional financial costs as a direct consequence of having a disabled child (Smyth & Robus, 1989).

Financial needs vary with particular LTIs and often according to the child's age. All groups except children requiring intensive medical resources (DG1) expressed the need at recruitment for help with issues related to the financial burden of caring, although subsequent interviews provided an opportunity for families in DG1 to report some needs regarding their financial situation. This is not altogether surprising as the children in this disorder group were not physically disabled and thus did not require adaptations to the family home or assistance with activities such as moving and handling, of which aids and equipment were reported by other disorder groups to be expensive. Only half of the families in this group received DLA, compared with two thirds of the intervention group as a whole, the majority of whom received the top level of benefit. Families of children requiring intensive medical resources (DG1) reported difficulty in accessing this form of financial assistance, while housing concerns expressed by this disorder group related to the need for help with negotiating with statutory organisations for housing benefits and assistance

with rent.

All disorder groups reported difficulties related to parental employment which had repercussions on the amount of money which they had at their disposal and frequently created situations which resulted in loss of earning power, findings which echo those of other studies (Baldwin, 1985; Stein et al, 1989). Mothers in this study had given up employment to care for their sick or disabled child, a finding consistent with Baldwin's (1985) and Smyth and Robus' (1989) studies which demonstrated that mothers were less likely to be in employment when compared with mothers in the general population. Several mothers in this study expressed the desire to work but could not find appropriate childcare or employment which would accommodated their child's school hours or an understanding employer who would be sympathetic to their need for time off for hospital appointments or at short notice when their child was ill. One mother wanted remuneration for assisting her disabled child in main-stream schooling due to the lack of available lunchtime support for which LEA funding was available. Conversely, another mother revealed a reluctance to seek employment for fear she would have less income than she received with benefits. Gainful employment, therefore, is frequently perceived as impossible due to the demands imposed by the LTI, a conclusion also noted by Hill (1994), While et al (1996a) and Kagan et al (1998).

The difficulties and dilemmas of families who know that their child is going to die before reaching adulthood caused concern for families of children with progressive degenerative disorders (DG2). These anxieties were reflected in their need for expert financial advice concerning paternal employment and pension issues. Although earlier research revealed that paternal employment and earnings are affected by the presence of LTI in the family (Baldwin, 1985; Smyth & Robus, 1989), no reference is made to the need for advice concerning future family finances once the child has died. This difficulty is clearly demonstrated in this study as the following quotation shows:

> "Our dilemma is whether (father) should go for a full time post and make life slightly more difficult at home with (child) later on, or be at home and do odd jobs and be the main carer so we don't have to pay so much child care as we are

> now, but have no pension. Eventually when (child) goes (father) is going to be of an age where it's going to be difficult to get back into full time employment. ..... It's just so difficult when someone dies, I mean nobody knows that so they just carry on as normal. But when you know, you have to plan for it (child's death), you don't know whether you're doing the right thing for her or the right thing for you". DG2 F9 T1

This illustrates the constraints of cross-sectional surveys which collect data at one point in time and thus may not capture the repeated and accumulating costs incurred, frequently over a period of many yeas, and that financial constraints and implications are likely to persist even after the child has died.

Analysis of serial data revealed that families of children with progressive degenerative disorders (DG2) and organ failure (DG3) expressed a Constancy of need regarding the need for structural changes to their homes which they considered were inadequate to meet fully their child's needs, a finding which mirrors that of earlier studies (Beresford et al, 1996; While et al, 1996a). Families expressed the need for structural adaptations with some families planning ahead to ease the future situation when their child's condition deteriorated to such an extent that ground floor accommodation was required. Families frequently cited stairs, lack of space and bathroom problems as increasing their caring burden, difficulties which were also noted by Baldwin (1985), Beresford (1995) and While et al (1996a).

Beresford et al (1996) recognised that the process of applying to Local Authorities for a grant for facilities for the disabled was often time consuming and problematic. Families of children with profound disability (DG4) in this study revealed that they had received some grant funding but had also contributed a substantial amount of money themselves, a finding consistent with the views of Hill (1994). Two families had received financial help to adapt their homes when their disabled children were infants. Difficulties had now arisen causing the families to express a need for further changes. Their children were now 10 years old and had outgrown the initial adaptations. This illustrates the need for a collaborative working approach between and across organisational boundaries to enable professionals to share information regarding a child's condition and prognosis when assessing present need and anticipating future needs so that appropriate plans can be made.

This study revealed that families in all disorder groups except those with children requiring intensive medical resources (DG1) expressed the need for additional finances to purchase aids to daily living such as bath, bed, mobility and lifting aids, and medical equipment for monitoring the child's condition and administering treatments. This confirms the views of Hill (1994). Some families actively fundraised to purchase items needed by their child such as an electric wheelchair. Interestingly, the need for aids and equipment was not expressed by families of children requiring intensive medical resources (DG1), despite families reporting the use of medical equipment in the home. Mechanisms for the provision of such equipment were already in place or assumed under the responsibility of acute health services who loaned equipment or ensured that it was readily available.

8.5.4 Extra Help with Practical Caring Need Zone

Obtaining some additional help with the practical aspects of caring for their child is fundamental to a family's ability to care effectively for their child. Three particular facets regarding need for practical help were revealed in this study: the need for respite care; assistance with daily life; and more specific help with particular aspects of daily care and treatments. Between a quarter and a third of intervention group families at recruitment expressed a need for additional practical help, such as with skilled child minding, respite care and practical nursing assistance. These findings support those of other researchers in that one of the most frequently reported unmet needs for families is obtaining some relief from the 24 hour responsibility of caring (Stein & Woolley, 1990; Beresford, 1995; While et al, 1996a). The extent to which needs were expressed within the social and practical need domains is further evidence that families are willing to share the burden of caring (NHS Executive, 1998). Nevertheless, this study showed that without appropriate mechanisms in place to facilitate this the burden of care invariably falls on the family alone. Often it is the lack of resources and expertise which prevent some areas from offering help in the family home (ACT & RCPCH, 1997).

Only five families had access to respite care at the local hospice, all of whom viewed this as an important resource. This is contrary to the findings of other

studies of patterns of hospice usage which revealed family reluctance to consider hospice care (Stein & Woolley, 1990), with children's hospices being solely associated with death and dying, a misconception derived from the adult hospice movement (Davies, 1998). Although families reported receiving tremendous support and comfort from the services provided by the children's hospice located within the study area, consistent with Stein and Woolley's (1990) findings, the amount of residential respite did not meet their needs.

Respite care for families should involve a range of services with families being able to chose a service appropriate to their child's needs. This study showed that, in reality, families had little choice with aspects of respite care such as the type of establishment, timing and amount of care. Families of children with progressive degenerative disorders (DG2) reported that their experiences with respite care were neither consistent, regular nor sufficient to meet their needs and this confirms the findings of other studies (e.g. Stein et al, 1989; Soutter et al, 1994; NHS Executive, 1998; Robinson & Jackson, 1999). Families of children requiring intensive medical resources (DG1) expressed the need for childcare during school holidays and this finding is consistent with Beresford's (1994) study which investigated children with disability. All families in the present study except those of children requiring intensive medical resources (DG1) expressed the need for day and night time respite care both in the home and in residential establishments. The group of families of children with profound disability (DG4) were not concerned with regularity and sufficiency of respite, nor did they specify the need during vacation time, they simply expressed the need for 'as much as possible', thus, further confirming the extent of the caring burden on this group of families and the degree of unmet need as reported by other researchers (Soutter et al, 1994; Beresford, 1995; Duncan & O'Flynn, 1995; While et al, 1996a).

Families of profoundly disabled children (DG4) were reluctant to criticise aspects of local authority respite care provision designed for children with learning and behaviour difficulties for fear that they would be perceived as

ungrateful or that the service would be withdrawn. This confirms the views of Betts and Mayer (1993) and ACT & RCPCH (1997) in that the lack of appropriate services is particularly apparent for families caring for children with complex health care needs or those who require any form of nursing or symptom management during periods of respite care. In part this supports working party recommendations made more than 10 years ago which suggested that it should be the responsibility of health authorities rather than SSDs to coordinate and provide respite care for this group of families (NAHA, 1988). However, findings from this present study proposed that the health and social needs of children with LTIs and their families were inextricably linked to such an extent that joint responsibility should be recognised within a collaborative framework involving all the statutory and voluntary services.

Difficulties with finding a babysitter able to administer medical treatments were revealed by families of children requiring intensive medical resources (DG1). For families of children with profound disability (DG4) a Constancy of need was expressed with the need for someone willing and able to deal with the practical consequences of complex disabilities such as moving and handling, feeding and suctioning. These examples of difficulties substantiate the findings of Stein et al (1989) and Sloper and Turner (1992) as difficulties in finding appropriate child care can seriously limit family life.

Problems concerning the recruitment of host families to participate in SSD 'link or befriending' schemes described by Stein and Woolley (1990) were also reported in this study. Linking families on a voluntary basis is attractive as it offers respite care in a home-from-home environment. However, recruitment of suitable host families is difficult for children with complex health and social care needs (Betts, 1994). The need for appropriate training of 'host' families by professionals willing to delegate health care tasks and the recognition of issues such as indemnity were raised to a managerial level which could influence policy planning and were demonstrated in this study.

Those respondents of children requiring intensive medical resources (DG1) and those with progressive degenerative disorders (DG2) reporting a reason for respite care other than to ease the general caring burden expressed a

need to enjoy a break with their spouse. Thus, respite care was viewed as an active coping resource to enable parents to spend quality time together. It was also seen as an important aspect in maintaining a positive partnership relationship and contributing to their ability to continue in their caring role. However, While et al (1996a) reported that some respondents did not use respite care services because they were concerned that it would indicate an inability to cope with their situation.

Having a child with a LTI substantially increases parental caring and household tasks and families expressed a need for assistance with their daily lives. Consistent with the findings of Beresford et al (1996) some families reported a preference for help with domestic duties while others expressed a need for nursing assistance and help with caring interventions (While et al, 1996a). A fifth of families at recruitment expressed a need for domestic help at home although this is only half the number reported by Beresford's (1995) national survey which may reflect the relative affluence of this study area with respondents able to pay for additional domestic help. Conversely, this may reflect the perceived unimportance which families placed on household chores, choosing instead to favour need for help with caring interventions. A key finding in this Extra Help with Practical Caring Need Zone which differentiated the disorder groups was the need expressed by families of children with profound disability (DG4) for assistance in the home with 'the extras' having a disabled child brings. This confirms Beresford's (1994) findings. Need for additional practical help thus appears to be diagnosis led, with Beresford (1994; 1995) reporting the need for help with domestic chores, and with While et al (1996a) reporting the need for help with caring interventions. These findings are confirmed in this study. Evidence from children with progressive degenerative disorders (DG2) is consistent with While et al's findings and evidence from children with profound disability (DG4) consistent with Beresford's study. This illustrates how a non-categorical approach to care provision would not distinguish between such differences families' need for additional help.

For families of children with progressive degenerative disorders (DG2)

assistance with daily life was reflected in the need for 'time'. More time in the day was needed to do things around the house. Caring interventions, therapies and treatments were time consuming and superseded household related tasks and other family activities. This confirms Goldman and Baum's (1994) supposition that time is a precious commodity for families with their child's treatments, care and quality of life often taking precedence.

A minority of families of children with progressive degenerative disorders (DG2) expressed the need for help with the rest of the family while they were resident with their child during periods of hospitalisation where they participated in their child's care (Cleary et al, 1986; Darbyshire, 1994; Coyne, 1995). Thus, parents had to make alternative arrangements for their healthy siblings, often at short notice. Unlike the minority of families in Tatman et al's (1992) study who were unable to stay overnight because of their other children, families in this study reported being resident in hospital. This likely reflected the LT nature of the disorders but further highlights the needs of healthy siblings of children with LTIs. This study showed that for professionals who practice to avoid the deleterious effects of separation between the sick child and family should practice family-centred care and recognise the dilemma of the resident parent who has responsibility for other family members at home.

Evidence of the burden of the caring role is further noted with respondents of children with progressive degenerative disorders (DG2) expressing a need for stimulation outside the home. The ability of mothers to articulate such a need may be reflected in the level of education and socio-economic standing of the study sample. Mothers reported giving up employment to care for their child. Stimulation outside the home did not simply mean an opportunity for gainful employment but also the chance for some quality time for themselves which they felt would enhance their ability to continue in their caring role. This is consistent with Beresford's (1994) findings.

The experience of taking care of their child on a daily basis confers expertise on parents (Dominica, 1990a; Jerrett, 1994). Thus, there is an understandable reluctance on the part of families to relinquish this expertise

and leave the child in unskilled hands (Whyte, 1992). This study confirmed families' need for help with their child's treatments and care and for nursing assistance to be available at short notice. What was important for families in this study was that assistance could be given by someone trained in specific aspects of their child's care. It is likely that voluntary services (e.g. Crossroads Care Attendant Scheme) which could match carers with individual children and train them to undertake specific interventions such as physiotherapy, suctioning and tube feeding would be a useful resource for families. This is consistent with working party evidence (ACT & RCPCH, 1997). This would have necessitated the training, delegation and supervision of carers by the researcher (or a knowledgeable health professional) echoing the service provided by Cole (1994). Although this study contributed to the debate regarding training and delegation of non-parent carers the data collection had been completed before any practical interventions of this nature could be initiated.

8.5.5 Information Need Zone

Knowledge and information are pivotal to a family's ability to manage their situation. Clear, accessible and timely information concerning the illness, treatments, prognosis and available services are absolutely necessary if families are to maintain or regain control of their family life and construct a method of coping which suits them. Families in all disorder groups expressed the need for assistance with acquiring appropriate information and this is consistent with the findings of many other studies (Quine & Pahl, 1989; Sloper & Turner, 1992; Beresford, 1995; Sloper, 1996; While et al, 1996a).

Some families of children with progressive degenerative disorders (DG2) and organ failure (DG3) wanted confirmation of a diagnosis and to discover the cause of the disorder. One respondent articulated the dilemma in which she felt caught between the need for answers and a reluctance to put her child forward for further investigations to try and determine a cause of distressing symptoms, despite the fact that determining the cause was one step nearer to the possibility of finding a cure. Having a definitive label for the disorder was also important for other reasons as this enabled families to access

disease specific self-help organisations which would facilitate contact with others in a similar situation and thus provide an opportunity to share information and experiences with other parents. This is consistent with Cornish et al's (1996) findings.

Two particular aspects regarding information concerning the disorder were specific to families of children requiring intensive medical resources (DG1). These families expressed the need for information about future treatments, the possible sequelae of such treatments and for an opportunity to discuss the child's progress with the specialist professional managing their child's care. These findings are not surprising in light of the disorders which comprise this group, for example cancer, where the focus of treatment is curative (ACT & RCPCH, 1997).

The need for information is an ongoing process which continues after the diagnosis period, as the child develops and as the family's needs change as the illness and / or the treatments progress. Families of children with organ failure (DG3) and profound disability (DG4) expressed the need for regular discussions with health professionals and thus, the opportunity to obtain information about treatments, symptom control and help with effects of the disorder such as feeding difficulties. A Constancy of need was identified in both these disorder groups further reiterating the importance of this type of help from specialist services. Interestingly, families of profoundly disabled children (DG4) also desired contact with health professionals as a listening ear, for someone who could empathise with their situation and offer suggestions to assist aspects of their practical caring role.

Families in all disorder groups expressed the need for additional information about local and tertiary services, which could offer practical help and advice. Such information was considered inaccessible, a factor perpetuated by the variety of services offered by the local provider organisations which families perceived as fragmented due to their differing organisational and management styles and structures. These findings are consistent with earlier studies (e.g. Sloper & Turner, 1992). The most frequent number of reported contacts with professionals from the statutory organisations for families in the

intervention group was nine, with the majority of contacts being with professionals across the range of health services provided within the study area as well as some tertiary health service contact. This further supports the findings of Sloper & Turner (1992). Interestingly, just less than half of families in the intervention group had no contact with an SSD and this is comparable with the number of families (54%) in Beresford's (1995) national survey who did not have a social worker. This would likely explain the lack of available information concerning issues such as benefits and sources of financial help both of which were required by families of children with organ failure (DG3). It also highlighted the educational needs of professionals with whom families did have contact.

The link between the Coping Resources and Strategies and Information Need Zones is further highlighted by the needs expressed by families of profoundly disabled children (DG4) for more information so as not to 'just manage' regarding aspects of their child's disability and likely prognosis. This need was constant over the study period with one family unable to ask for the level of services they required and appearing resigned to never having enough information. This lack of motivation in seeking out information confirms Beresford's (1994) findings which suggested that the process of actively seeking information empowers families in their caring role.

Families of profoundly disabled children (DG4) also expressed the need for information about sources of respite and other specialist services in the locality which would avoid the need to travel away from the family home. This emphasis on the need for information about sources of practical help was specific to this group of families (DG4). It further illustrated that the burden of care was especially great for this disorder group, with families having little time spare to seek out information and, as Beresford (1994) proposed, less able to demand the level of services they felt their child was entitled to.

Another important theme concerned the need for information exchange between and across organisational boundaries and for procedures which would enhance communication processes between professionals and families. Families of children requiring intensive medical resources (DG1)

expressed the need to participate in their child's management but without appropriate information did not know what to ask and were thus dis-empowered in their caring role. Families of children with progressive degenerative disorders (DG2) dominated this theme in that the poor level of information exchange between the various statutory services and particularly the tenuous links between primary and tertiary services were a source of anxiety and an area in which families expressed a need for improvement. Families even articulated the need for someone to coordinate services within a key worker framework:

> "There has got to be a static person who really knows the job, knows everybody else who you can meet. One person who tells you that yes, I'm here for you, I will be at the end of the phone, if there are any problems I will sort it out and get somebody who knows the job to get back to you". DG2 F3 T1

This fully supports the findings and recommendations of NAHA (1988); Woolley et al (1991); Soutter et al (1994); Beresford (1995); Duncan & O'Flynn (1995); While et al (1996a); ACT & RCPCH (1997); NHS Executive (1998); Proctor et al (1999). The quality of information exchange between family and services and the level of parental participation in their child's care were two factors which may influence family need and were common to all disorder groups, whereas the extent to which a child's care was coordinated and the degree of the family social network were particular to children with progressive degenerative disorders (DG2) and children with organ failure (DG3). Controlled nursing research studies examining the implementation and evaluation of a key worker role with families of children with LTIs are required. There is also a need for qualitative studies to verify factors affecting family need such as the quality of information exchange and the level of parental participation.

8.5.6 Equipment and Resources Need Zone

One third of families reported a need for help with obtaining medical equipment and aids to daily living to facilitate their caring role and these findings mirror those of numerous previous studies (e.g. Kohler & Radford, 1985; Meltzer et al, 1989; Soutter et al, 1994; While et al, 1996a). The disorder groups differed in their need for aids and equipment with the need

for assistance expressed on a continuum. At one end families of children requiring intensive medical resources (DG1) expressed a need for the servicing and repair of medical equipment which they already had in their possession, (more than one quarter of families (29.6%) reported that they had purchased such equipment themselves). Families of children with profound disabilities (DG4) were at the other end of the continuum and revealed a Constancy of need for daily living aids.

Families of children with progressive degenerative disorders (DG2) expressed a need for numerous issues within this Need Zone, most extensively for medical equipment to administer treatments and perform therapies (such as nebulisers for specialist medication and physiotherapy equipment). Analysis of data from families of children with organ failure (DG3) revealed a Constancy of need for medical equipment to administer treatments and to assist in the control of symptoms. For example, one child with inoperable CHD required oxygen therapy to assist restlessness at night. This aided sleep for both child and mother who frequently attended the child at night. Families expressed the need to try out equipment before purchasing as equipment is expensive and not always appropriate for the child's needs. This raises the issue of responsibility for funding and provision of equipment. It was evident in this study that no statutory organisation had taken lead responsibility, with families frequently caught in the friction between organisations regarding funding and provision issues. This is consistent with other studies (e.g. Audit Commission, 1994). This study illustrated the need for a central source of funding to improve the provision of equipment and disposable items, rather than a key worker trying to co-ordinate their provision within and across different organisational boundaries. This confirms the recommendations proposed by the recent working party (ACT & RCPCH, 1997).

All disorder groups except children requiring intensive medical resources (DG1) expressed the need for aids and equipment to assist their child's daily living activities. These findings also reflect those of earlier studies (Smyth & Robus, 1989; Beresford, 1994; While et al, 1996a). The need for structural

adaptations to housing has been discussed within the Extra Help with Costs of Caring Need Zone. However, the need for specialist furniture, for example, bed, bath and mobility aids were required by these three disorder groups. Such items facilitate the caring role, ease the caring burden and thus improve the child's quality of life. It is imperative, therefore, that mechanisms are in place which can assess a child's needs and provide what is needed without delay and without the friction and confusion between SSDs and health services over responsibility and funding. A collaborative working approach by professionals is thus required which would considerably lessen the caring burden and anxiety experienced by families.

Specific to families of children with progressive degenerative disorders (DG2) was the need for aids and equipment to enable their child to participate in main-stream schooling. Very few studies in the literature have included an investigation of the child's school environment. If, as Lavelle (1994) commented, education should be accessible to all children then it is important that future studies explore the difficulties experienced by children at school, to reduce parental burden and anxiety and enable children with LTIs to participate as fully as their peers. A more collaborative working approach across the statutory services would enhance a child's access to education and improve quality of life.

The need for intersectorial working was a theme strongly illuminated with regard to equipment and resources by all disorder groups except for children requiring intensive medical resources (DG1). Needs were expressed which would necessitate a collaborative working approach among professionals in order to solve particular problems. For example, families of children with profound disability (DG4) desired solutions to problems concerning housing issues which would necessitate health services and SSDs sharing information. Families of children with progressive degenerative disorders (DG2) expressed the need for help with accessing mobility benefits and help with housing in which health and SSDs were also required to work together. In addition, a collaborative approach among professionals from the different health sectors to facilitate access to tertiary services which could act as a

specialist resource to other professionals and the family was also revealed. Families of children with organ failure (DG3) wanted health and education services to work together to solve problems with equipment for symptom control needed at school and concerning appropriate forms of transport to school.

This study recognised the difficulties of families of disabled children less than five years of age who were not entitled to receive the mobility component of the DLA and thus were unable to access a motability scheme to purchase an appropriate vehicle. This supports Beresford's (1994) and Howard's (1995) earlier findings. Families of children with organ failure (DG3) expressed a need for easy access to hospital in an emergency situation and for easy parking. Few families had access to an 'orange badge' to facilitate parking in areas designated for the 'disabled'.

Difficulties with getting out and about were illuminated in the study with more than one quarter (25.9%) of families expressing a need for help with transport related problems and with more than one fifth of families at recruitment reporting extra expenditure on travel costs to hospital. With the exception of children requiring intensive medical resources (DG1) all disorder groups expressed the need for help with obtaining a suitable vehicle in which to transport their child and which would also accommodate the child's equipment and the rest of the family. These problems were highlighted by the parents of a profoundly disabled child (DG4) who enlisted the help of extended family members to go away on holiday. Two cars were needed, one for the disabled child and equipment and the other to accommodate two siblings and luggage. Such difficulties experienced by families with disabled children mirrored the findings of Sloper & Turner (1992) and Beresford et al, (1996).

Whether or not families had access to an aids and equipment loan service was a factor likely to influence a family's level of need and was common to all disorder groups. Other factors which probably affected need for additional help were the suitability of the child's environment (home and school) and the availability of appropriate transport. In addition, the quality of care

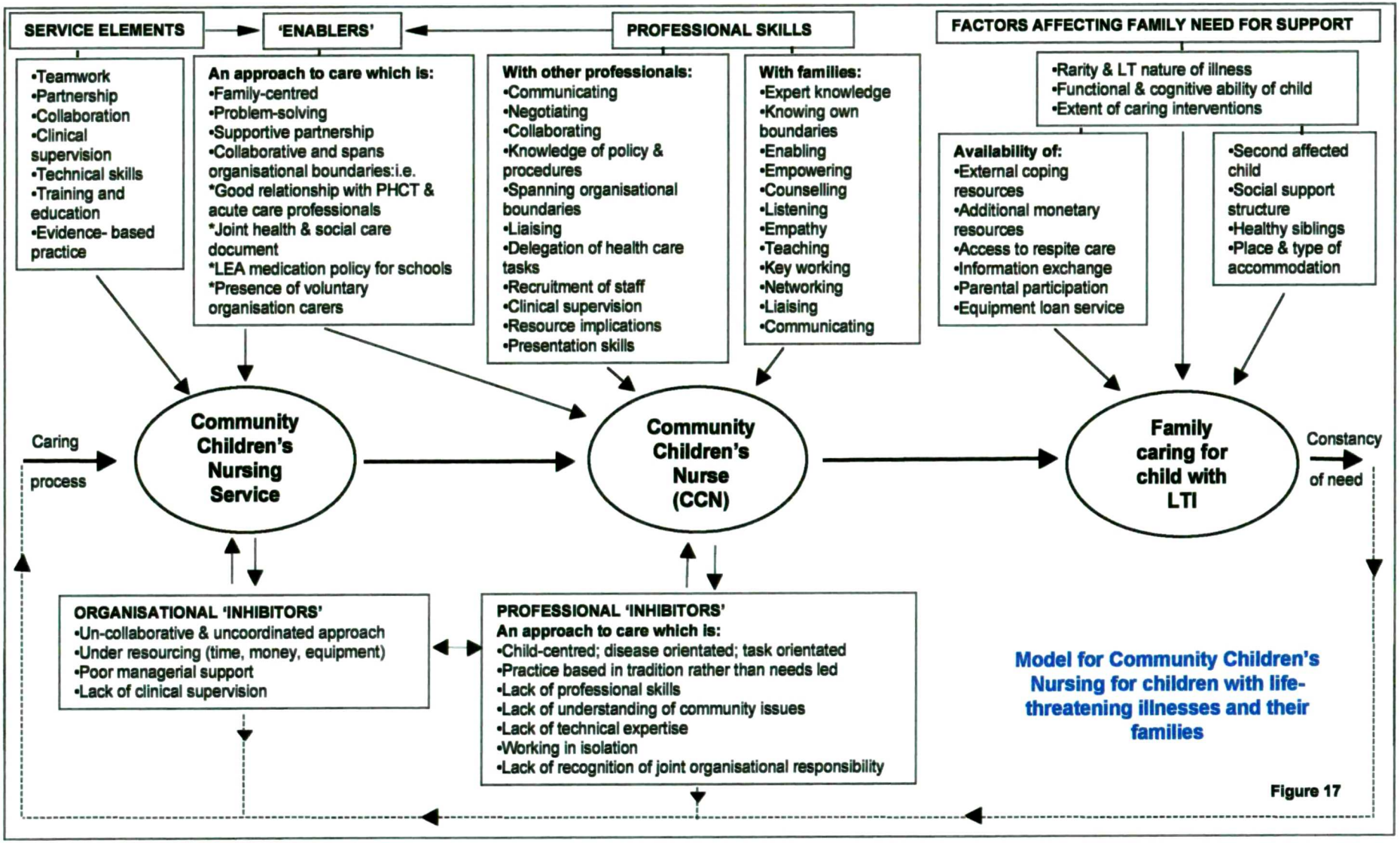
coordination and the extent of collaboration between the different organisations was also likely to influence the degree of family need but these issues warrant further research.

8.6 Community Children's Nursing

8.6.1 Model for Community Children's Nursing for children with life-threatening illnesses and their families: Commentary

Findings from the quantitative and qualitative components of the study were merged in the development of a dynamic model for community children's nursing (Figure 17). This CCN model should be useful to the newly formed Diana Nursing Teams as their client group is consistent with this study. A variety of factors are likely to influence the degree and type of family need for support and additional help. Certain factors such as parental resources, social support structure, place and type of accommodation and the presence of other children lie outside the legitimate domain of professional nursing practice but are included as these are areas which generate unmet need. Other factors such as the rarity and LT nature of the illness, the functional and cognitive ability of the child and the extent of caring interventions required are themes which were consistently identified throughout the six Need Zones. Several factors which were likely to affect family need were identified in all disorder groups and were Need Zone specific. These related to the availability of: external coping resources; additional monetary resources; access to respite care; quality of information exchange between professionals and family; an equipment loan service and the extent to which parents are empowered to participate in their child's care. A Constancy of need was identified in some disorder groups and Need Zones, illustrating the dynamic nature of need and the requirement for continual assessment and reassessment.

In the model professional skills are identified as qualities essential to the CCN to bring about effective service delivery.



Model for Community Children's Nursing for children with life-threatening illnesses and their families

Figure 17

Skills are distinguished between those required to work with families and those with which to interact usefully with other professionals. The CCN is assisted in his/her role by service elements which value qualities such as: teamwork; partnership; collaboration; clinical supervision, maintenance of therapeutic knowledge and skills and nursing research. More importantly, however, the presence of four 'enablers' facilitates the role. These are firstly, an approach to care which considers the whole family rather than focusing on the sick child. Secondly, one which enables and empowers families to find solutions to their problems. Thirdly, an approach which contributes to the development of a supportive partnership relationship between family and CCN. Finally, the fourth 'enabler' to effective service delivery involves the development and maintenance of a collaborative working approach to enable families to traverse organisational boundaries effortlessly. Organisational and professional 'inhibitors' to effective service delivery were also extrapolated from the data and are included as they affect the quality of service delivery and contribute to the negative feedback mechanism in the caring process as such constraints are likely to be partly responsible for Constancy of family need.

8.6.2 Professional skills

Nurse-led interventions initiated by the researcher occurred within three distinct areas, firstly, on an individual basis with families; secondly, with issues common to particular groups of families; and thirdly, in contributions to operational and strategic planning to raise the profile of the new CCN service. It was essential to convince the commissioners of health care that the CCN service was viable, valuable and effective. The stringent financial climate in the public sector meant that there was serious competition for funds. Opportunities for service development which required considerable expenditure were minimal and funds for new initiatives needed to be diverted from existing community services, a finding consistent with that of Lessing and Tatman (1991).

The researcher carried out 241 visits with families during the data collection period and spent just less than half (45%) of her time available each month

on family related care. A further 11% of time was spent performing the series of interviews with families which were considered as having therapeutic value. Families reported that they had not had the opportunity to discuss their needs and relate 'their story' in such a manner before and this is consistent with Linker's (1982) findings. This highlighted the importance of allowing parents to set the tone of the interview and of using the structured and semi structured methods to gather information. Thus, the interviews could be viewed as an additional method of providing support. No studies of a similar nature are available in the literature to make a comparison regarding contact time with families, non-patient related activity and service delivery coupled with research. The study evaluating Loddon NHS Community Trust (Nursing Standard Reports, 1996) revealed that CCNs spent an average of 75% of their time on patient care. Specialist nurses from tertiary centres (e.g. CF nurse) aim to spend 80% of time available within the community environment (Duce, 1999 personal communication). The researcher spent less time than this in patient related activities, but the research component was time consuming and without this the researcher would have had more time available for caring interventions with children and families.

The majority of visits with families occurred within the family home although contact was also made with children in schools, nurseries and respite care facilities. Parents were not always present during these visits, however, permission was always sought prior to seeing children in the care of other statutory professionals. This occurred as part of the process of negotiating a care plan with families, consistent with Dale's (1996) model. Thus, they were not just informed as to what was happening with their child's care but were involved in developing the partnership relationship the aim of which was to ensure that they participated as fully as possible in their child's care and management. Collaborating with other statutory service professionals involved the use of a range of skills including: communication, knowledge of policy and procedures and delegation of health care tasks.

Contact with families also occurred by telephone. The geographical area of

the study was one health district with all families living within a 20 mile radius of the researcher's base in a GP surgery and health centre. Nevertheless, telephone contact with families allowed queries to be discussed and frequently saved time spent travelling. On the few occasions the researcher gave her home telephone number to be available out of office hours this privilege was not abused by families. When calls were made these invariably involved families checking about some aspect of their child's care which needed support, advice or encouragement. Often families just needed confirmation that they were doing things correctly and did not require a home visit. This is consistent with Norman and Bennett's findings (1986).

Few practical, 'hands on', caring interventions with children were undertaken, although the researcher was equipped with the technical skills, or acquired skills and extended her knowledge base as necessary, for example, by networking with nurses from specialist tertiary centres. The researcher did not practice from a task-orientated approach but from one which viewed it as fundamental to empower parents in their caring role and to enable them to find solutions to difficulties associated with interventions which exceeded normal parenting skills. This analysis revealed a move away from the task-orientated approach of the CCN described by Dryden (1986; 1989a; 1989b) to one outlined by While (1991) and Whyte et al (1998) where advice, support and listening took precedence and were considered major interventions which parents described as being offered by CCNs. This approach is similar to the third level of skill identified by Proctor et al (1999) in their review of CCN services. They suggested that this level of practice encompassed community perspectives associated with health promotion services such as health visiting. These findings are contrary to those of Tatman et al (1992) who revealed that 57% of their sample (n=47 children) received practical nursing care from the home care team. In this study the researcher undertook practical interventions alongside emotional support and help and thus an integral part of the CCN role concerns both support and practical skills which occur simultaneously.

Twice the number of visits were undertaken with profoundly disabled children

(DG4), and almost twice the amount of researcher time (hours available) was spent with these families compared with time spent with those requiring intensive medical resources (DG1). This confirms the findings of researchers who have studied children with disabilities (e.g. Baldwin & Carlisle, 1994; Beresford, 1995). The caring burden for these families was great and they were in considerable need of additional caring services to share this burden and to obtain resources and develop strategies to help them in their caring role. These findings are unsurprising for a number of reasons. Firstly, children requiring intensive medical resources (DG1) had frequent access to secondary and tertiary health professionals with whom they could discuss any problems, including professionals who were able to visit at home (e.g. oncology outreach nurse and children's asthma nurse). Secondly, the majority of children with progressive degenerative disorders (DG2) were in the early stages of their illness. However, their prognoses predicted that all would lose their independent mobility within four - six years which would increase considerably the caring burden on their family. This is consistent with the model proposed by Baum (1994) in which he described the progression of family burden with particular manifestations of an illness and the speed with which change occurs to be factors which significantly affected the needs of the child and family.

8.6.3 Professional 'inhibitors' to effective service delivery

The semi-autobiographical accounts obtained from families during the recruitment interview revealed, in many instances, factors which affected negatively the care which they received from an array of professionals and services prior to the research and the initiation of home care. Such professional 'inhibitors' were the antithesis of 'enablers' and were characterised by practice steeped in tradition rather than led by the needs of the population. This concept was also identified in evidence presented to the House of Commons Health Committee (1997). Issues such as a lack of understanding of community issues and a disease or task-orientated approach which was frequently child rather than family-centred were criticisms leveled at acute care professionals by families in this study. This is

consistent with the findings of Proctor et al (1999) in their description of first and second levels of skill which they suggested reflected the origins of the CCN service in hospital nursing. Professionals based in the community were frequently cited as lacking in up to date technical skills and were often reported to work in isolation. This supports the findings of Peace et al (1994) and Beresford (1994). The study also identified a lack of recognition of joint responsibility for children whose health and social care needs were inextricably linked. For such children the researcher acted as a key worker to ensure that holistic care not just health care was provided and consistent with palliative care working party recommendations (ACT & RCPCH, 1997). Therefore, this study has revealed the need for services which incorporate the benefits of the two dominant models of CCN service delivery (While & Dyson, in press), i.e. community based and hospital outreach models, into the structure and delivery of care.

The extent of the workload and the need to provide 'cover' during periods of absence was further evidence that the structure of the CCN service should comprise a team of more than two WTE nurses who can work effectively together to provide care for sick and disabled children at home. Such undesirably low core staffing levels were revealed in a substantial number of CCN teams in While and Dyson's (in press) national review. The size of the team is obviously dependent on the needs of the population to be served and the geographical nature of the locality. Three WTE CCNs would be adequate for the study area in present circumstances as the University teaching hospital situated in the study area employed specialist nurses who carried out some home care for children with cancer and asthma (4.4). Children with profound disabilities also fell under the umbrella of the Children's Disability Team (CDT) (4.4). Formal opportunities to foster liaison, co-operation and a more collaborative working approach with these nurses by the researcher would have enhanced care for families in the study area by providing enough nurses to offer a 24 hour on-call system of care and support.

Few teams provided a 24 hour service in While and Dyson's (in press) review, although Proctor et al (1999) revealed that five of the six sites in their

study offered 24 hour provision. This is probably due to the large number of nurses (n=>10) in the CCN teams evaluated and is further evidence of the unrepresentativeness of their study sample. The researcher was aware that offering her home telephone number for 24 hour availability to some families meant that the service as a whole was not equitable and could lead to unsustainable expectations for families and work overload for the researcher, a finding consistent with Proctor et al's (1999) work. The minority of families to whom the researcher offered her home telephone number found this to be beneficial and did not abuse the privilege. It is undeniable that availability of 24 hour care was beneficial for families in this study, however, controlled evaluative research is required to validate this statement, a view also proposed by Proctor et al (1999).

8.6.4 Organisational 'inhibitors' to effective service delivery

Organisational constraints which prevent effective service delivery can also be surmised from this study. A service which functions in isolation and fosters a lack of respect for collaboration and cooperation with other service providers will not be able to deliver an optimal service and is unlikely to meet the needs of families which it serves. Under-resourcing i.e. in time, money and equipment can also impede the delivery of effective and quality care. It is important therefore, that the commissioners of CCN services are provided with robust evidence on the effectiveness (e.g. financial breakdown and quality of life issues) of these services, for example, in reducing periods of hospitalisation or length of hospital stay.

The presence of the generic CCN sister appointed after the research had commenced (1.2) may have confounded the study somewhat but provided the researcher with the opportunity for support on a daily basis. This facilitated the sharing of problems and ideas and provided reciprocal 'cover' for periods of annual and study leave and illness. This supports the findings of While and Dyson (in press) who identified a substantial number of CCN teams which functioned with a minimal staffing level and the associated difficulties. Formal methods of psychological support are essential for all

CCNs working with families and this finding is consistent with working party recommendations (ACT & RPCH, 1997). Poor managerial support and lack of clinical supervision were not experienced by the researcher although the lack of a supportive working environment might easily hamper the way in which a CCN practices by fostering feelings of isolation.

8.6.5 Service elements

Essential structural components for the delivery of an effective CCN service can be extrapolated from aspects of the CCN role identified above. The researcher developed and maintained strong links with both community and acute care organisations to engender a partnership and team working approach among all professionals involved with individual families. One of the fundamental aspects of the CCN role is, therefore, the ability to traverse organisational boundaries and it is proposed that the CCN is often best placed to co-ordinate care and liaise between the different services. This confirms working party evidence (NAHA, 1988). A collaborative approach is likely to be facilitated where the organisation has a fully integrated child health department unlike the situation in the study area. This has the support of the House of Commons Health Committee (1997).

The ability to keep up to date with technical skills and learn new skills is important for CCNs working outside acute care situations. The researcher had neither a formal community qualification nor experience of working in the family home. Nevertheless, her considerable nursing skills obtained in a tertiary centre with families caring for seriously ill children were successfully transferred to the family home. However, these specialist skills were underused and relatively unimportant in that the fundamental aspects of the researcher's role were the 'enablers' discussed below (8.6.6).

8.6.6 'Enablers' to effective service delivery

Interventions were reflected upon so as to tease out key aspects of the CCN role as practiced by the researcher. Four fundamental themes underpinned

interventions with families and other professionals and are perceived as 'enablers' to an effective CCN service. Essential structural components and professional nursing skills contribute to these 'enablers'.

8.6.6.1 Family-centred care

Family-centred care has been widely proposed as integral to the provision of care for sick and disabled children for many years (Sciarillo, 1980; Jolly, 1981). Yet evidence from this study revealed that some families experienced a disease or task-orientated approach, particularly from acute sector professionals. Families perceived that care focussed exclusively on their child and did not consider the needs of the family as a whole. This confirms evidence presented by Valentine (1998). It also directly contravenes good practice guidelines (Department of Health, 1991; NHS Executive, 1996), but is consistent with the findings of Proctor et al (1999) who found such evidence in their "inverse cases" (page 50) where families reported detrimental effects from a lack of appropriate support.

8.6.6.2 A problem-solving approach to care

A problem-solving approach to care which enabled and empowered families to find solutions to their problems was evident in the analysis of nurse-led interventions. Effective communication processes involving the reciprocal exchange of information between the researcher and family facilitated this approach. This involved the researcher utilising effective interpersonal skills within an appropriate setting (the family home) in unhurried circumstances. Listening to families and clarifying their expressed needs preceded the discussion of potential solutions. This is consistent with Davis' (1993) and Dale's (1996) supposition of qualities fundamental to a successful partnership. This problem-solving approach encouraged real parental participation in care by allowing the researcher to develop a body of knowledge regarding the wishes, skills and expertise of families and discovering parental expectations about their caring role. Concurrently, the formation of a positive relationship with the researcher enhanced parents' ability to use the researcher as a coping resource to obtain information and

develop a body of knowledge and expertise themselves. Active coping strategies such as these are likely to be associated with greater levels of family well being. This finding supports Baldwin and Carlisle's (1994) and Beresford's (1994) conclusions. Thus, the informal 'unspoken arrangement' concerning parental participation revealed by Darbyshire (1994) was identified as an explicit aspect of the CCN role. Such an approach facilitated families regaining or maintaining control of their family situation and was important in their search for empowerment. This finding supports Canam's (1993) assertion that a positive influence of successful adaptation to living with childhood LTI is parents' ability to manage their child's care on a daily basis.

8.6.6.3 Development of a supportive partnership relationship

The efficacy of any caring organisation is dependent upon the quality of relationships which develop between professionals and patients and their families. This study revealed that the development of a supportive partnership relationship was a positive factor in reducing family needs and can be viewed as an 'enabler' to an effective CCN service. Contributing factors to a successful partnership were the family-centred and problem-solving approaches to care discussed above. The identification of need and discussion regarding possible solutions to problems fostered a commitment between researcher and family to work closely together. The ensuing negotiation to find ways to meet child and family need demonstrated the emphasis on the need for equality in the partnership, reduced the likelihood of conflict and increased mutual respect for each others skills and expertise. These findings are in accordance with Dale's (1996) Negotiating Model. A flexible approach to the needs of the partnership was also required of the researcher as parental coping strategies and family needs changed during the study period. Therefore, relationships with families were on going and dynamic and constantly evolving, a phenomenon revealed by While (1992) and Casey (1993) and analogous to Baum's (1994) Model depicting the progression of family burden associated with LTIs.

8.6.6.4 A collaborative working approach

A collaborative working approach with other professionals was identified as the fourth 'enabler' to effective service delivery. Effective collaboration requires mutual understanding of the roles and responsibilities of all those professionals involved with a family. This study revealed a lack of definition for the CCN service and this was highlighted in the need for the researcher to network extensively with primary and secondary health professionals to elicit their support prior to commencing data collection and interventions. This is consistent with Gow and Campbell's (1996) findings. Some professionals in the study area considered the advent of an additional service unnecessary and perceived it as a threat to their own role, corroborating the views of Charlton and Macaulay (1993) and similar experiences were reported by CCNs in Proctor et al's (1999) study.

Mechanisms were initiated by the researcher to network with and inform other professionals such as the GP and PHCT about the CCN role and responsibilities. Strategies included attending practice, HV and SN meetings. Frequent visits to paediatric ward areas and special schools were made and multidisciplinary management team meetings were attended monthly. Contact was established with individuals from SSDs and main-steam schools in joint planning and training for individual children once a plan of action had been negotiated with the family. These strategies are consistent with recommendations from studies evaluating CCN services (While 1991; Tatman et al, 1992; Jennings, 1994; Gow & Campbell, 1996; Nursing standard Reports, 1996) and literature describing the CCN role (Kelly, 1998). The researcher was based in the community and this facilitated effective liaison with community and SSD professionals but made it more difficult to maintain therapeutic knowledge and skills. This supports While and Dyson's (in press) findings and demonstrates the need for formal procedures to enable CCNs to attain and maintain professional practical nursing skills.

Examples of collaboration among the statutory and voluntary organisations in this study were identified. The evolving good relationship with PHCT and hospital care professionals where mutual respect for the specific roles,

responsibilities and contribution to families were important. Discussion between health and social services was instrumental in the development of a joint health and social care document which addressed issues such as the delegation of health care tasks to non-parent carers. Similarly, the development of a medication in schools policy supported school staff with the administration of a variety of drugs required by children during the course of a school day. Collaboration with organisations in the voluntary sector occurred and ensured that their expertise was used to their full potential. It is not possible to plan a comprehensive service without cooperation and collaboration between the voluntary and statutory services (Thornes, 1990).

8.7 Limitations of this study

For several reasons a pre-test needs assessment was not performed with the control group. Firstly, it was considered unethical to identify needs in control group families and then not be able to respond to those areas of unmet need. Secondly, time constraints and obligations to the employing community NHS Trust prevented the use of a more controlled evaluative study. The researcher had sole responsibility for designing the research process, collecting and analysing data, initiating the nurse-led interventions with families and intervening within the organisation to raise the profile of the CCN service. This serves to highlight difficulties faced by practitioners undertaking research in their own field of practice (Whyte et al, 1998).

Cook and Campbell (1979) argued that post-test data should be collected by someone other than those responsible for providing the intervention(s) in order to reduce the risk of bias. The researcher was aware of potential threats to the internal validity of the study, for example, developing different depths of relationships with families of differing personalities and that very 'needy' families may have required extensive interventions to the detriment of others. The researcher was also aware that demanding families may have impinged on her time and that 'less vocal' families might not fare so well. An awareness of such issues enabled the researcher to give every family an equal chance of utilising the CCN service and to minimise their effects as much as possible.

The level of global need scores expressed by the control group were not significantly different from the intervention group at the final interview (Time 3) and were significantly lower than the intervention group at recruitment (Time 1). This suggests that whilst the intervention group's needs were reduced, the effect may have been more generalised. The quasi-experimental design permits interpretation of results which establish links between cause and effect (Burns & Grove, 1993). Issues such as blinding, patient and clinician preference (Bradley, 1993) and ethical issues relating to equipoise may create problems when services are being evaluated by this method. However, randomisation may be more ethical than inflicting an untried and potentially harmful service on families and that disparity between service supply and demand often means that only part of a population can be served at any one time (Beresford et al, 1996).

Over the period that elapsed before control group families were interviewed there were a number of changes in local services which may have improved provision for all families, thus confounding the study. For example, a community children's nursing sister was appointed by the Community NHS Trust six months after the study was underway. Her role and responsibilities did not fall within the remit of the study but she accepted referrals from all health sectors and had contact with a large minority (n=6) of families of children with LTI allocated to the control group. She offered continuity of care for children following acute hospital treatment and it is likely that she also responded to other areas of family need in her nursing role as she visited them at home.

The 'Hawthorne' effect (Mayo, 1949) may be responsible because control group families were brought to the attention of a key health professional during the nomination process. Any unmet family need may have been identified and met from an alternative source other than from the community children's nursing sister (for example, by a health professional from the PHCT) during the period between nomination and interview. Furthermore, anticipation of future meetings with the researcher and the potential access to services through the study may have influenced the responses given by

families in the intervention group, thus eliciting a different depth of response between families interviewed three times and those control group families interviewed only once. This finding is consistent with Linker's (1982) study.

A degree of sample attrition was expected. However, some health professionals (HVs, SNs and one specialist nurse) who had identified families in the nomination survey refused to approach a family with the introductory information inviting them to participate. Some health professionals wanted to limit professional contacts while others wanted to save the researcher time from approaching families they knew would not participate. This form of selection bias was out of the control of the researcher and meant that families were not given the opportunity to choose whether or not to participate. Thus, some families in need may have been denied help by well meaning professionals.

In the absence of standardised measures to assess the needs of families caring for children with LTIs a tool needed to be developed and this limited the study as time constraints and the small sample size prevented internal validation of the modified perceived needs scale. Further research is required to examine the internal validity and therefore the usefulness of this tool with families of children with LTIs.

The small sample size precluded analysis of nurse-led interventions by disorder group and this is clearly a limitation of the study. However, significant differences in functional ability and caring intervention scores between the disorder groups were noted. Although no significant differences were seen in mean global need scores between the disorder groups, qualitative analysis of expressed need revealed differences across the disorder groups in all Need Zones. As interventions were initiated in response to expressed need and with factors likely to influence need related to functional ability and the caring interventions performed by parents it is probable that nurse-led interventions had a different focus across the disorder groups. This tentative link suggests that further research is required

to examine CCN interventions with families and to compare them in a more controlled fashion against child and family outcomes.

No specific qualitative approach or philosophy was used and this may be considered a limitation to the study, although the guided thematic approach used by the researcher was proposed as a useful method of deepening understanding of a situation by Miles and Huberman (1994). As the initial component of the study was quasi-experimental a stratified random sample of families was selected to participate as intervention and control groups. Had a qualitative approach prevailed then a purposive sample might have been used to include 'typical' families in 'typical' situations (Burns & Grove, 1993) to enhance further the theoretical understanding of childhood LTI and the contribution made by the CCN. For these reasons the sample size was too large for a qualitative study as the amount of data generated from the 79 interview transcripts were immense. Hence the need to analyse only a portion of the data pertaining to the expression of current need for additional help, i.e. 'the expressed need data', which was considered a manageable amount of data from which in depth analysis of the continuing care needs of families could be undertaken.

The frequency of some illnesses represented in the study was small and the generation of a detailed list of children and their specific characteristics would have increased the chance of families being identified. Thus, combining the 16 illnesses of the original sampling frame into four disorder groups (4.3) enabled the clustering of data which resembled each other but preserved family anonymity. Children were grouped because they were similar, either diagnostically or in their need for particular types of services. Assigning children to one of the four disorder groups occurred early in the qualitative analysis process and this enhanced comparison of themes among and between disorder groups. However, subsequent to the generation of these four disorder groups working party evidence (ACT & RCPCH, 1997) proposed a four disorder group classification of LTI and life-limiting illness which differed slightly in composition to those used by the researcher. It is possible that findings from this study might have differed if this classification

had been used. This may be considered a limitation and replication of this study using the ACT & RCPCH (1997) guidelines may further enhance our understanding of the needs of families.

Despite these limitations the expressed needs of intervention group families were reduced significantly during the period in which the principal change in service provision for them was the introduction of nurse-led interventions. The random allocation of those receiving caring services to one of two groups where only one receives the intervention being tested is one of the best methods available of attributing an effect to a particular intervention (Oakley, 1996). The financial constraints under which all statutory services operate within budgets means that robust research evidence regarding the effectiveness of services is required for the maintenance and development of all caring services. Therefore, future studies of this nature should be controlled, with interventions evaluated by the measurement of child and family outcomes.

Chapter 9 Conclusions and Areas For Further Research

The emotional, physical and financial distress for families following a diagnosis of childhood LTI is considerable and long lasting as the daily burden of care, co-existing with the threat of death, predominately falls on parents. Appropriate and timely services are essential to enable families to attain or maintain control and manage their child's illness in an environment in which they and their child feel comfortable. The shift in emphasis from hospital to home care for an increasing number of children with LTIs has undoubtedly amplified the need for effective care and support for families in their own homes.

As technological and scientific advances continue to improve the life expectancy and prognoses of these children so the need for community children's nurses to facilitate and co-ordinate care in the family home has also escalated. Presently, only 50% of health authorities purchase CCN services (House of Commons, 1997) therefore many children with LTIs and their families do not receive optimal care and support to which they are entitled. The expansion of CCN services is urgently required to create a degree of uniformity throughout the country and conformity with adult services. This is consistent with recommendations from several recent publications (While et al, 1996a; ACT & RCPCH, 1997; House of Commons, 1997; NHS Executive, 1998) and is reiterated because this service is vital if families are to feel supported in their caring role.

The interviews with families confirmed the findings of previous empirical work in that families continue to have unmet need concerning information, practical support in the home and with obtaining some relief from the 24 hour responsibility of care. The psycho-social effects experienced by all family members, the need to develop coping strategies and the financial implications of care have also been recognised. It is a cause for concern that families continue to express a need for additional help with such issues despite evidence of unmet need already in the public domain.

This was the first quasi-experimental study examining the role of the CCN in relation to meeting the needs of families caring for children with LTIs at home. There were difficulties with design and methodology. The lack of a pre-test interview with control group families limited direct comparison between intervention and control groups and the presence of the generic CCN sister appointed after the study had commenced may have confounded the findings. Time constraints prevented internal validation of the modified perceived needs scale and the researcher's combined provider and research role coupled with responsibilities to the employing organisation may also have limited the findings. Despite these limitations, however, it is clear that the levels of expressed need were reduced significantly in intervention group families during the study period in which the principal change in service provision for them was the introduction of nurse-led interventions by the researcher under the auspices of the newly formed CCN service.

The micro, mezzo and macro levels of qualitative analysis of 'expressed need' data confirmed Eiser's (1993) assertion that it is difficult to distinguish between the benefits of a non-categorical approach and one which advocates specific interventions for particular disorders. Initial analysis at the micro level revealed the disorder groups to be unique. However, themes generated on the mezzo level of analysis revealed some commonality among disorder groups, with complete commonality being identified at the macro level. Due to the rarity of childhood LTI and therefore the relatively small number of children involved this is the level at which community health care services are generally provided. A principal aspect of the role of the researcher was, therefore, the ability to deliver family-centred care on a micro level (specific to the needs of individual families) while working within the constraints of an organisation which provided a service on a macro level i.e. from a non-categorical approach.

Analysis of interventions revealed the need for numerous nursing skills with families and with other professionals which reflected a move away from a task-orientated approach to one where advice, support and listening took precedence. This mode of practice is consistent with the third level of skill

identified by Proctor et al (1999) and encompasses community perspectives associated with health promotion services such as health visiting. A key finding from this study is the need for CCN services to incorporate the benefits of community based and hospital outreach models into the structure and delivery of care.

Four fundamental themes underpinning nurse-led interventions with families and professionals were revealed and are perceived as 'enablers' to an effective CCN service. These are an approach to care which 1) focuses on the whole family; 2) enables and empowers families to find solutions to their problems; 3) reinforces the development of a supportive partnership relationship; and 4) one in which effective collaboration among professionals enables families' care to span effortlessly the numerous organisational boundaries. Therefore, one of the key aspects of the CCN role is the ability to traverse organisational boundaries and it is proposed that the CCN is often best placed to co-ordinate care and liaise between the different services. The proposition of a model incorporating these 'enablers' provides a framework for nursing practice and for the development of community children's nursing knowledge with children with life-threatening illnesses.

A number of questions, however, remain and should form the basis of future research:

- Is the CCN / Diana Nurse the most appropriate professional to co-ordinate care and management for children with LTIs?
- What are the fundamental principles of CCNursing / Diana Nursing which enable effective and quality service delivery?
- How does the CCN / Diana Nurse enable and empower families caring for children with LTIs to manage their situation?
- What is the role of the CCN / Diana Nurse in the multi-professional team?

The findings of this study provide an empirical basis for contributing to the development of CCN services particularly at this time of the introduction of the Diana Nursing Teams. However, further work is clearly needed. Well

designed, controlled, multi-centre, evaluative studies of the role and effectiveness of the Diana Nursing Teams and other CCN services providing care to this client group are required.

Appendices

Appendix 1 List of diagnoses pertaining to life-threatening illness

This was not designed as an exclusive list but was used as the basis for the development of an operational definition of childhood life-threatening illness.

All malignant disease
All progressive degenerative disorders
Cystic fibrosis
The dystrophies
Rett syndrome
Blood disorders such as beta thalassaemia major
Primary immune deficiency disorders
Acquired Immune Deficiency Syndrome
Inborn errors of metabolism
Arginosuccinase deficiency
Lactic acidosis
Diabetes mellitus (children who have required admission to hospital in keto-acidosis more than once in the last year - excluding presenting symptoms)
Osteogenesis imperfecta < 1 year of age
Major organ disease
Cyanotic heart disease
Cardiomyopathy
Liver disorders / biliary atresia
Renal failure
Nephrotic syndrome
Severe asthma (high dose inhaled steroids and bronchodilators and regular steroid tablets: (Step 5 BPA management of chronic asthma in children)
Apnoea
Severe epilepsy (children admitted to hospital in status epilepticus within the last year)
Severe allergy problems and potential for anaphylaxis (Adrenaline / epinephrine carried at all times)
Children requiring immunosuppression therapy following organ transplantation
Children requiring parenteral / enteral nutrition
Children requiring home oxygen therapy
Children with a tracheostomy
Any child in danger of collapsing at home, where the parents have received training in resuscitation techniques from health professionals.

Appendix 2 Modified perceived needs scale

The following questions relate to various forms of help which parents or carers of a child with a serious illness sometimes need. When answering these questions please indicate the response which best corresponds with your family's level of need over the last four weeks.

1. Getting enough help
2. Already getting some help but would like more
3. Not getting any help but need it
4. Not getting any help but don't want it
5. Not applicable / not a problem

Q1. Do you feel you need advice or information about [child] illness / condition?

Q2. Do you feel you need the chance to discuss [child] progress at least every 3 months?

Q3. Do you feel you need information about services in general that are available for sick children in this area?

Q4. Do you feel you need help with improving [child] mobility?

Q5. Do you feed you need help with transport problems which occur because of [child] illness / condition?

Q6. Do you feel you need help with obtaining special equipment / aids for [child]?

Q7. Do you feel you need help at home with the rest of the family while you are resident in hospital with [child]?

Q8. Household chores often get neglected when there is an ill child in the family, do you feel you need some domestic help at home?

Q9. Do you feel you have a need for some special help to take care of [child] during the day which would enable you to go out to work?

Q10. Do you feel you need measures to improve your housing which are necessary because you have a sick or disabled child?

Q11. Do you feel you need extra financial advice and/or help as a result of [child] illness / condition?

Q12. Do you feel you need access to special educational facilities/ opportunities for [child]?

Q13. Do you feel you need help in coming to terms with [child] illness / condition?

Q14. Do you feel you need help with marital / partnership difficulties that are caused by [child] illness / condition?

Q15. Do you feel you need help with difficulties that arise with other members of the family as a result of [child] illness / condition?

Q16. Do you feel the need for an informal support network. A sounding board or someone to listen to you about the problems, stresses and strains of having a sick or disabled child?

Q17. Do you feel you need nursing assistance with caring for [child] at home?

Q18. Do you feel you need skilled help with child-minding or baby-sitting for [child]?

Q19. Do you feel the need for a link between hospital and home?

Q20. Do you feel the need for a link between hospital and school?

Q21. Everyone needs a break from their children) every now and again. Do you feel you need a break or some respite from the 24 hour responsibility of taking care of [child] at home?

Appendix 3 Functional ability scale

With regard to [child] ability to undertake the following activities of daily living, please indicate the statement which best describes [child] at the moment. (Indicate one statement only in each question except for special care).

Mobility
Can walk independently
Crawls, rolls, shuffles or walks with an aid
Has limited mobility requiring assistance.
Immobile

Feeding
Eats unaided
Eats with an aid (e.g. special cutlery)
Needs some help and encouragement
Needs supervision
Needs to be fed
Requires skilled feeding / nasogastric or gastrostomy feeding.

Continence
Has full bladder and bowel control
Is occasionally incontinent
Is totally incontinent of urine and or faeces
Has a urinary catheter / ostomy.

Pressure area vulnerability
Skin is intact and child is able to turn without help
Needs turning at night
Needs frequent changes of position day and night
Already has one or more pressure sore(s).

Getting dressed
Dresses self
Requires some assistance
Needs to be dressed
Requires changes of clothing several times a day or needs to have appliances fitted

Personal hygiene
Washes / bathes self
Needs some help or supervision with bathing
Is unable to bathe self
Needs more than one person for moving / washing / bathing / toileting.

Communication
Indicates needs verbally
Uses other forms of communication effectively (makaton, Blissboard) or has limited speech
Indicates some needs non-verbally
Has no effective means of communication.

Behaviour
Integrates / relates to surroundings normally
Participates in activities with help
Needs to be stimulated
Requires mealtime supervision
Is hyperactive and inclined to wander
Is disruptive or inclined to aggression or has a behaviour problem needing frequent intervention.

Awareness
Is fully aware of surroundings
Is aware of surroundings but has poor concentration skills
Is partially aware of surroundings
Is totally unaware of surroundings

Fit pattern
Does not have fits
Has minor fits or spasms
Has major fits
Has frequent fits / powerful spasms
Has uncontrolled fits / spasms which require treatment with a complex drug regime.

Special care(s)
Has an infectious condition
Needs regular oro/nasopharyngeal suction
Has a tracheostomy
Needs other nursing intervention (specify)
Has a complex drug regime)
Requires 1:1 constant care (family)
Requires 1:1 constant care (nursing)

Appendix 4 Semi structured interview schedule (prompts)

Who was present when you were told about the diagnosis?
(Spouse, hospital consultant, other doctor, ward sister, social worker, child, psychologist, GP, health visitor, other.)

Where did this interview take place?
(Hospital office, hospital bedside, corridor, GP surgery. OPD, other)

Who told you the news?
(GP, consultant, other doctor, ward nurse, spouse, other)

Where did you get your help and support from at this time?
(Family, spouse, nurses, doctors, health visitor, GP, social worker, friends, other)

Do you feel closer as a family, or has the experience of having an ill child separated you?

What activities are you able to participate in as a family?
(Daily outings, holidays, holidays abroad, shopping, other)

In what kind of ways are you restricted as a family?
(No holidays, difficulty leaving the house, financially, can't use public transport, isolated from friends, no outings, isolated from family, other)

Have you incurred any extra expense with having an ill child?
(Buying equipment, housing modifications, drugs, aids, special holidays, other)

Do any family members feel neglected because [child] needs so much care?

What changes would you like seen made in the 'system'
(Better communication, co-ordination of services, key worker, shared care, nurses at home, other.)

Appendix 5 **EDUCATIONAL NEED DOMAIN (TIME 1 RECRUITMENT INTERVIEW) (CG = CONTROL GROUP)**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	a) Collaboration between secondary health and education services	a) Enhanced communication processes across the service interfaces b) Training for school staff - with practical health care interventions	• Sees school staff as lacking in interest • Would like hospital staff to speak to school • Wants school to pay more attention to the child's needs • Wants health professional to speak to school • Wants school to have more information about the disorder and treatments • Wants school to be more responsive to child's needs • Feels teachers and helpers need training and education about disorders & treatments • Wants mainstream school staff to have help to be able to support child • Wants a link between hospital & school to train school to deal with emergency treatments • Confirmation of health status to arrange free bus pass (CG)
	a) Collaboration between therapy and education services b) A focus on skills acquisition c) Collaboration between primary health and education services d) Partnership between education & family	a) Practical help and advice with making adaptations to main stream school environment b) A focus on academic achievement c) Practical help with administration of medicines d) Discussion regarding need for educational statement	• Would like help to get school organised. e.g. ramps built before child starts school • Concerned about child's progress at school, wants more attention paid to reading and writing • School staff (main stream) to monitor child taking medication (CG) • School staff (main stream) to supervise administration of medicines (CG) • Speech therapy 1:1 assistance when starting main stream school (CG) • Individual help with speech therapy (CG) • Discussion regarding the need for a statement of special educational need (CG)
G3	a) Partnership between education services and family b) Collaboration between therapy and education services c) Collaboration between secondary health and education services	a) Enhanced communication and information giving processes between school and family b) Practical help from therapists c) Enhanced communication across the service interfaces	• Need for more info from school about child's learning difficulties • Need for a discussion with school staff, want to avoid being perceived as over anxious • Thinks child needs a 1:1 LSA in school • Perceives special school staff lack motivation, needs school to see child from her point • of view (she knows child best) • Speech and language assistance at main stream school (CG) • Health services to keep school (main stream) up to date promptly(CG)
	a) Collaboration between therapy and education services b) Acceptance of social skills training	a) Practical help from therapists b) Enrichment of child's life (i.e. for children to be able to do things which they enjoy)	• Child's LSA can speak for child on parents behalf at school but would need a link between hospital and school if 1:1 was not there • Mother would like child's schooling to include things she enjoys i.e. swimming and • horse riding • Trained physiotherapist needs to be present if child is to go horse riding • Mother would like child to have a 1:1 LSA who could take her swimming

Appendix 6 **EDUCATIONAL NEED DOMAIN TIME 2**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	a) Collaboration between secondary health and education services b) Partnership between education services and family	a) someone to act as a link between health services and school b) Enhanced communication & information giving processes between school and home	• Wants to know which school child will be attending • Wants info from school regarding child's newly diagnosed learning difficulties • Want someone to act as a link between health and school rather than self
2	a) Collaboration between therapy and education services b) A focus on social skills acquisition	a) Practical help from therapists to enable child to take part in all school activities b) Social skills development	• Child needs 2 people in PE lessons to be able to participate • Wants physiotherapist to be available to help child with particular activities and skills at School e.g. PE, music and drama
DG3	a) Collaboration between therapy and education services b) A focus on safety	a) Practical help from therapists b) For child to be educated in a safe environment	• Wants child to be safe at school (child has been injured by peer) • Wants child to receive appropriate amount of speech therapy at school (rather than paying for Private tuition)
	a) Partnership between education services and family b) A focus on safety c) Acceptance of social skills training	a) a full time LSA for child b) For child to be educated in a safe environment c) Enrichment of child's life (i e. for children to be able to do things they enjoy)	• Wants child to be safe at school (has been injured by peer). Has kept child off school until something can be sorted. • Does not want child to miss out on things she enjoys • Would like a full time LSA to support the child at school have been told there is no money for this

Appendix 7 **EDUCATIONAL NEED DOMAIN TIME 3**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	No expressed need coded		
DG	a) Collaboration between therapy and education services	a) Practical help from therapists b) Completion of adaptations to main stream school environment	• Need toilet / changing facilities at school to be completed, started 9 months ago. Mother says it's up to school to pay. • Wants physio to liaise with school to comply with OT suggestions re covering changing surface.
DG3	a) Therapy and education services to collaborate. b) Social skills improvement.	a) Practical help from therapists	• Dilemma not sure whether she wants to pursue speech therapy difficulties with school or not. Difficult to know what to do to improve child's social skills.
	No expressed need coded		

Appendix 8 **EMOTIONAL NEED DOMAIN TIME 1 (RECRUITMENT INTERVIEW) (CG= CONTROL GROUP)**

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	a) Managing the child / children b) Supporting the extended family c) Coming to terms with long term nature of disorder	a) support group b) contact with other affected families c) respite from the burden of daily care d) trustworthy childcare e) information	▪ Feels needs help in coming to terms with the disorder, but feels should have come to terms with it due to the length of time since diagnosis ▪ Needs help with dealing with two children who are affected ▪ Needs to talk to other affected families, others don't understand ▪ Coping with illness through experience wants to be a resource to others (not a support gp) ▪ Needs help with close relatives who don't understand the difficulties ▪ Would like help in paying for counselling to help deal with situation ▪ Need trustworthy people to child-mind. "Finding someone you can trust". ▪ Would like health professionals to offer information rather than having to keep asking for it ▪ Not happy with treatment management by health. ▪ Wants support group to be there if she should need it in the future ▪ A support group for (disorder) sufferers and carers (CG)
2	Intervention group - No expressed need coded a) Coping with taking care of child b) Supporting extended family c) Managing the situation d) Coping with what the future holds	a) support network b) contact with other families in same situation c) for extended family to understand d) disclosing prognosis to sibling e) discuss worries with professional not family / friends	▪ Extended family to be able to understand situation(CG) ▪ Strategies to explain things to well sibling (CG) ▪ Support during times of stress when child's condition being assessed(CG) ▪ To talk to professional about worries rather than a friend(CG) ▪ To talk about fears to someone not involved with situation (scared of upsetting family and friends(CG) ▪ Help with dealing with poor prognosis(CG) ▪ Someone to lean on for emotional support(CG) ▪ Child to be able to mix with other affected children(CG)
DG3	a) Coping with what the future holds b) Managing daily life	a) support network b) information c) empathy from professionals regarding worries	▪ Need for someone to talk to who understands medical and health issues i.e. a professional rather than lay person ▪ Planning ahead, may need help to coming to terms with child's impending deterioration ▪ Recognises own need to explore issues about child dying with spouse ▪ It would be nice to have some help in coming to terms with the disorder, no example ▪ Need info about and help with accessing an informal support network when feeling down about everything ▪ Strategies to deal with potential loss of child (CG) ▪ Strategies to deal with worries of everyday life
	a) Managing daily life b) Sustaining the family c) Supporting other family members	a) respite care away from home b) time (i.e. not enough time in the day to do everything)	▪ Need for someone to talk to when upset ▪ Need for help to run the home & deal with siblings activities as well as the disabled child ▪ Need for help with everyday living in the home as marriage does suffer ▪ Respite care needed for child so that the well sibling can get away from the disabled child situation, for her to "try and have some normality in her life" ▪ Mother needs to devote more time to sibling to help him with school work

Appendix 8 EMOTIONAL NEED DOMAIN TIME 1 (RECRUITMENT INTERVIEW) (CG= CONTROL GROUP)

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	a) Managing the child / children b) Supporting the extended family c) Coming to terms with long term nature of disorder	a) support group b) contact with other affected families c) respite from the burden of daily care d) trustworthy childcare e) information	▪ Feels needs help in coming to terms with the disorder, but feels should have come to terms with it due to the length of time since diagnosis ▪ Needs help with dealing with two children who are affected ▪ Needs to talk to other affected families, others don't understand ▪ Coping with illness through experience wants to be a resource to others (not a support gp) ▪ Needs help with close relatives who don't understand the difficulties ▪ Would like help in paying for counselling to help deal with situation ▪ Need trustworthy people to child-mind. "Finding someone you can trust". ▪ Would like health professionals to offer information rather than having to keep asking for it ▪ Not happy with treatment management by health. ▪ Wants support group to be there if she should need it in the future ▪ A support group for (disorder) sufferers and carers (CG)
D 2	Intervention group - No expressed need coded a) Coping with taking care of child b) Supporting extended family c) Managing the situation d) Coping with what the future holds	a) support network b) contact with other families in same situation c) for extended family to understand d) disclosing prognosis to sibling e) discuss worries with professional not family / friends	▪ Extended family to be able to understand situation(CG) ▪ Strategies to explain things to well sibling (CG) ▪ Support during times of stress when child's condition being assessed(CG) ▪ To talk to professional about worries rather than a friend(CG) ▪ To talk about fears to someone not involved with situation (scared of upsetting family and friends(CG) ▪ Help with dealing with poor prognosis(CG) ▪ Someone to lean on for emotional support(CG) ▪ Child to be able to mix with other affected children(CG)
DG3	a) Coping with what the future holds b) Managing daily life	a) support network b) information c) empathy from professionals regarding worries	▪ Need for someone to talk to who understands medical and health issues i.e. a professional rather than lay person ▪ Planning ahead, may need help to coming to terms with child's impending deterioration ▪ Recognises own need to explore issues about child dying with spouse ▪ It would be nice to have some help in coming to terms with the disorder, no example ▪ Need info about and help with accessing an informal support network when feeling down about everything ▪ Strategies to deal with potential loss of child (CG) ▪ Strategies to deal with worries of everyday life
	a) Managing daily life b) Sustaining the family c) Supporting other family members	a) respite care away from home b) time (i.e. not enough time in the day to do everything)	▪ Need for someone to talk to when upset ▪ Need for help to run the home & deal with siblings activities as well as the disabled child ▪ Need for help with everyday living in the home as marriage does suffer ▪ Respite care needed for child so that the well sibling can get away from the disabled child situation, for her to "try and have some normality in her life" ▪ Mother needs to devote more time to sibling to help him with school work

Appendix 10 **EMOTIONAL NEED DOMAIN TIME 3**

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	a) Managing the situation	a) contact with other mothers in same situation	• Wants to visit other mothers for support or a chat but can't because most have cats.
	a) Coping with what the future holds b) Managing the situation	a) help in coming to terms with the disorder b) to be able to take each day as it comes rather than be forced to confront the future	• Admits there is a need but can't cope with coming to terms with the disorder • Wants to take each day as it comes rather than "having someone lay it out in front of me".
DG	a) Coping with what the future holds	a) support from parents in same situation who are further on in the illness trajectory b) help with impending surgery	• Wants to talk to another family who have been through the same situation but are further down the line. • Don't want child to go through surgery again but know that they have no choice.
	No expressed needs coded		

Appendix 11 **FINANCIAL NEED DOMAIN TIME 1 (RECRUITMENT INTERVIEW) (CG = CONTROL GROUP)**

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	No expressed need coded		
D	Housing issues a) Present b) Future c) Loss of earning power d) Aids to daily living & equipment e) Employment difficulties	Financial assistance with: a) structural adaptations to home b) Bath aids c) personal pension advice d) part time employment (for extras like a holiday)	▪ Would like help with plans & adapting council accommodation for future when child wheelchair bound ▪ Needs adaptations to accommodate child in near future ▪ Adaptations to house needed for child and family ▪ Very concerned about housing adaptations needs help with planning for future ▪ Would like financial help to adapt house as family want rather than as council say ▪ Planning housing adaptations "before need arises" ▪ Planning adaptations to family home on advice from voluntary organisation ▪ Need for specialist bathroom equipment ▪ Need to borrow money to adapt house. Would like a grant if one was available ▪ Need financial advice on personal pensions concerning dilemma over being in employment or becoming a full time carer for the remainder of the child's lifetime ▪ Need financial advice on personal pension planning for future after child dies ▪ Financial advice and planning need by independent personnel ▪ Need more accommodation in home for equipment for physio treatment ▪ More space i.e. a spare room for equipment, drug storage and treatments (CG) ▪ A second toilet (mother and child have bowel problems) (CG) ▪ An extension for therapy equipment (CG) ▪ Part time employment for little extras like a holiday (CG)
DG3	Housing issues a) Present b) Future c) Aids and equipment d) Employment difficulties e) Transportation	Financial assistance with: a) structural adaptations to home b) bed, listening aids c) equipment for monitoring condition and for treatments d) financial assistance with travelling to tertiary centre e) worthwhile job to make up for losing benefits	▪ Need downstairs accommodation for child in future – planning ahead and also to make room for equipment (oxygen concentrator) ▪ Child needs a bed with cot sides under finances because it is money that is preventing them ▪ Need for an intercom to hear child same reason as above ▪ A worthwhile job to make up for losing benefits (CG) ▪ Financial assistance for travel costs to tertiary centre (CG)
	a) Transportation	a) financial assistance to purchase appropriate vehicle	▪ Need to change transport, people carrier to accommodate child's wheelchair and equipment ▪ Need financial help to be able to afford an appropriate mode of transport ▪ Need a large deposit to join motability scheme to purchase appropriate vehicle for push in wheelchair ▪ Need help and advice on the financial implications of making adaptations to housing but have no choice but to afford the car

Appendix 12 **FINANCIAL NEED DOMAIN TIME 2**

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	Housing issues: a) Present b) Loss of earning power	a) housing benefit & council tax rebate b) Alternative work pattern	• Needs housing benefit and council tax rebate – with child being ill husband only able to do contracting – so doesn't get paid for days off
2	Housing issues: a).Present b).Future c) Employment difficulties	a) financial assistance with structural adaptations to home b) part time employment around school hours c).payment for helping at school	• Wants a job for a bit of extra money but restricted by school hours – also if child sick can't go to work • Doesn't want anyone else looking after child if went to work • Wants school to sort out lunch time supervisor for child as doing it herself unpaid • Need adaptations to housing (council) 15x15 foot room • Wants to know what is happening with process of housing alterations i.e if need to move or have an extension • Wants a sunny garden for child to play in (in dispute with neighbours over leylandii trees!)
DG3	Housing issues. a) Present	a) financial assistance with structural adaptations to accommodation	• Siblings need separate bedrooms – sick child's treatments / monitor cause disruption to older sibling
	Housing issues. a) Present b) Future c) Employment difficulties d) Aids to daily living e) Transportation	Need financial assistance with. a) purchasing appropriate one storey accommodation b) bungalow accommodation c) structural adaptations to home d) grant to contribute to extension which is approved e) aids to mobility f) cash deposit to join motability scheme g) childcare to be able to go out to work / college	• Need to buy a bungalow suitable for disabled child - can't do this because don't have the finances • Would like £50,000 and to sell house to buy suitable single storey family accommodation • Extension approved but need to find money to put towards grant (not even sure if they are eligible for a grant) • Wants to go out to work but can't unless "you're loaded to get a nanny in" • Wants to go to college to do a course • Wants to go to night school but needs a reliable babysitter • Need a cash deposit to be eligible to join the motability scheme

Appendix 13 **FINANCIAL NEED DOMAIN TIME 3**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	a) Accessing benefits b) Employment difficulties	a) help with completing DLA forms b) to go back to work after child's treatment complete	• Need help with filling out DLA forms • Would like to go back / out to work but feels has to wait until child's cancer treatment is completed as has to visit hospital once a week.
2	Housing issues: a) Present b) Future c) Employment difficulties	a) financial assistance with structural adaptations to home b) part time employment around school hours	• Would like to get a part time job but it would have to be something which fitted around school hours • Wants a downstairs toilet but because they mentioned to DSS that husband may move jobs they were given a chemical toilet instead which mum has to empty • Housing issues – want to know sooner rather than later what is going to happen i.e. whether they will need to move or whether the grandfather will let his house be adapted
DG3	Housing issues: a) Present	a) financial assistance with structural adaptations to home	• Wants downstairs bedroom for child, need help with liaising with social services regarding finances
	No expressed need coded		

Appendix 14 **INFORMATIONAL NEED DOMAIN TIME 1 (RECRUITMENT INTERVIEW) (CG = CONTROL GROUP)**

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	a) Concerning the disorder b) Regarding services in the locality c) Intersectorial information exchange	a) to participate in management but don't know what to ask b) to keep up to date with new treatments c) about the treatment d) regular reviews of the child's progress	▪ Says knows how to get info but in same sentence asks what the tablets are for. ▪ You don't know if you need information until you're given it. Gives example ▪ Wants more help with obtaining info about the specific disorder no example ▪ Mother wants information to keep up to date ▪ Mother concerned that treatments may change and she may not know about it due to lack of hospital check-ups ▪ Wants to keep up to date but feels that the onus is on the family to be vigilant for new treatments / advice etc ▪ Would like 6 monthly reviews with consultant to see where child's "at with everything" ▪ Wants 6 monthly appointments with hospital rather than being discharged and having to rely on the GP ▪ Wants info on complimentary therapies to use alongside conventional treatments ▪ A definite request for more info about the specific disorder implies doesn't believe health professionals who say there isn't any ▪ Would like to know what is available with regard to services but in same sentence says if You're not going to use the info do you need it? ▪ Information about condition and treatment (CG) ▪ Information about types of help available for (condition) sufferers and carers (CG)
DG2	a) Regarding services in the locality b) Intersectorial information exchange c) Concerning the disorder	a) hospital to share information with other key professionals b) keyworker c) to keep up to date with new treatments d) enhanced communication processes between hospital and family e) information about motability benefits f) information about leisure and entertainment for disabled g) about statutory services h) about disorder treatments	▪ Need a list of people or services which are available ▪ Need info on where to find help when it is needed ▪ Need for a list of people and their speciality available to help ▪ Need for a "static person who knows the job" and "knows everybody else who you can meet" ▪ Need a list of services other than medical and health which are available i.e. services providing support and entertainment ▪ Need for regular OPD appointments to review progress on finding the diagnosis (CG) ▪ Need equipment for performing physio treatments (CG) ▪ Need for information on research issues concerning the disorder to keep abreast of new treatments (CG) ▪ Need some more help with info about services in the area (CG) ▪ Information needed about treatments to be put in writing for other professionals (CG) ▪ Need info about appropriate schooling for the child – planning for the future ▪ Would like more info on the availability of services perhaps in the form of a leaflet ▪ Need info about benefits particularly motability and how the scheme works

DG2 C nt			▪ Need for "somebody that's permanent" and not going to pass you on to other services ▪ Need for someone static to be there at the end of the telephone ▪ Need someone who really knows the job and knows everybody else ▪ Need for a person at the end of the phone to sort out problems or get someone to sort it out ▪ Need for a network to ring about leisure and entertainment for disabled children ▪ Keyworker, someone to help find out about services in the area ▪ Information on how to access hospital services to avoid lengthy waiting on ward ▪ Information on disorder which is offered and readily available ▪ Information on how to access therapy services
DG3	a) Concerning the disorder b) Regarding services in the locality	a) help with living with effects of disorder b) sharing information with new parents a) Regular discussion with health professional b) information about sources of financial assistance e) services for children under 5 years of age in the area	▪ Need info about child's condition but difficult as parents know as much as consultant ▪ Need info about services in the area appropriate to their needs "we don't fall into any particular category" ▪ Would like chance to discuss child's progress 3 monthly as condition is deteriorating and causing anxiety ▪ Need information about the disease which is not contradictory ▪ Would like the chance to be seen 3 monthly and know that there is someone is there if needed ▪ Need more information and help with the effects of the disorder i.e. feeding difficulties ▪ Would like to share information with others ▪ Need to know what services are available ▪ Need information on sources of financial help and advice for housing adaptations due to having 4 children and ill child needing own room ▪ Information about what's going on in the area for under 5's (CG) ▪ Information about services in the area SPECIFY (CG)
	a) Concerning the disorder b) Regarding services in the locality	a) regular discussion with health professional b) information about, respite services c) help with understanding the disorder	▪ Would like chance to discuss progress with health professional as neighbours don't understand ▪ Would like info on just exactly what services are available ▪ Has a need to understand about a particular part of child's disability ▪ Needs to find out about a babysitting service

Appendix 15 **INFORMATIONAL NEED DOMAIN TIME 2**

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	a) Concerning the disorder b) About child's progress c) Relating to treatment sequelae d) Regarding services in the locality	a) opportunity to ask questions b) 6 monthly 'parents evenings' with consultant Information about: c) prognosis d) treatment and future treatments e) side effects of treatments f)Clear and accessible information	• Wants to know how the treatments are working • Wants information about the effects of treatments • Wants more information from the consultant about the treatment and future treatments • Wants clearer information about services • Wants easily accessible information about services in the area • Wants the opportunity to ask questions • Would like a parents evening once every 6 months like at school to ask questions without the child being around • Wants information about the prognosis now that treatment in well under way
	a) Concerning the disorder b) Regarding services in the locality	a) Confirmation of diagnosis - to try and prevent acute episodes Information about: b) Services which are easily accessible c) Availability of practical help	• Wants information about services in the area • Wants a diagnosis – to find out what is happening in order to try and prevent acute episodes from happening • Wants information on the availability of any practical help • Wants information that is accessible and easy to find out
DG3	a) Concerning the disorder b) Regarding services in the locality c) Intersectorial information exchange d) About specialist / tertiary services	a) to find out cause of illness b) child not to be put through more tests but needs answers c) information from HV about local services d) to know if child will need extra help at school Information about: e) treatments for symptom control f) what to expect at tertiary centre	• Wants to find out what is causing the illness • Doesn't want to put child through more tests but wants to get to the bottom of the problem • Wants information about specialist / tertiary referral centre • Wants information about oxygen treatments • Wants to know if child will need extra help at school • Wants information about services thinks HV should offer information
	a) Regarding services in the locality	a) for specialist services in the area rather than London Information about: b) availability of services c) services which is easily accessible	• Wants a specialist (disorder) consultant in the area • Wants information about services available in the area • Wants information that is easily accessible and available • Need a deposit for a new car to be able to join the motability scheme • Needs GP to sign benefit form, difficult to get to see him

Appendix 16 **INFORMATIONAL NEED DOMAIN TIME 3**

DG	Themes for disorder group - higher range of abstraction	Thematic development - middle range of abstraction	Summary of verbatim quotations
	a) Concerning the disorder b) Relating to treatment sequelae c) Regarding services in the locality	Information about: a) treatments and future treatments b) drug side effects c) services which are specific to child's condition	• Wants info about drug side effects - didn't know until very recently that some common analgesics can trigger an asthma attack • Want as much info as possible however simple about drugs and side effects • Wants to arrange a hearing assessment for child with cancer who has had a lot of ear infections and antibiotics
	No expressed need coded		
DG3	a) Concerning the disorder b) Relating to treatment sequelae	a) the opportunity to discuss general child issues b) information about treatments	• Wants the chance to discuss general child issues like behaviour and bedwetting (likely to be related to illness and drugs anyway)
	a) Concerning the disorder	a) more information so as not to 'just manage'	▪ Information about disorder - "we manage"

Appendix 17 PRACTICAL NEED DOMAIN TIME 1 (RECRUITMENT INTERVIEW) (CG = CONTROL GROUP)

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	a) Medical equipment	a) for servicing and repair b) to administer treatment c) to monitor condition	▪ Would like to have nebuliser serviced locally rather than send it back to manufacturer ▪ Would like not to be without nebuliser when sending it for servicing and repair ▪ Need replacement parts for their nebuliser ▪ Equipment – a nebuliser rather than borrowing from health centre (CG) ▪ Need a piece of equipment to monitor condition (keeping a disorder diary) (CG)
	a) Medical equipment b) Transportation c) Intersectorial working	a)equipment to administer treatments b) equipment to perform therapies c) appropriate sized vehicle d) lack of transport	▪ Need for a larger car to transport electric wheelchair ▪ Wants to avoid the wait until eligible for the mobility motability scheme ▪ Need for a link between hospital and home or liaison example given test results ▪ Need for physio equipment ▪ Need for a tipping frome for physiotherapy ▪ Need for washable covers on tipping frame ▪ Need for physio equipment in near future ▪ Need for bigger house to accommodate equipment ▪ Need for a portable nebuliser to take abroad ▪ Need for a nebuliser on standby because "when you need it you don't have it" ▪ Would be useful to have a link between hospital and home rather than just ringing the ward to speak to a paediatrician ▪ Need for a link between hospital and home due to difficulties with transport getting to hospital ▪ Equipment - nebuliser for new treatment ▪ Equipment - tipping frame for physio ▪ Equipment - portable tipping frame which packs away & suitable for holidays ▪ Transport - future needs - appropriate transport for wheelchair (CG)
D 3	a) Medical equipment b) Transportation	a) to administer treatments b) to monitor condition c) emergency transport to hospital d) easy parking at hospital e) logistics of travelling	▪ Need for nebuliser at home at all times example one on loan from HC they "do ring and ask for it Back!" ▪ Need help with getting to hospital quickly or in an emergency ▪ It would make life easier to have trouble free parking at the hospital ▪ Transport – difficulties and costs of frequent visits to tertiary centre
	a) Aids to daily living to deal with large scale movements of child (in present and future situation) b) Transportation (for dealing with present and future situation)	a) mobility aids, hospital type bed b) adaptations to home (i.e. lift) c) appropriate vehicle to avoid lifting child; to accommodate equipment and rest of family	▪ Planning ahead for the need to update size wise child's wheelchair ▪ Need proper transport facilities to avoid lifting the child in and out of the car ▪ Need for a suitably adapted vehicle which can accommodate a push in wheelchair ▪ Adaptations required to housing to avoid carrying child upstairs ▪ Need appropriate facilities for large scale movements of the child i.e. too the car, to upstairs, in the bathroom / hoist, lift ▪ Future planning for need for appropriate transport to be able to get wheelchair in ▪ Need some sort of method to advertise and sell second hand equipment ▪ Need for appropriate mobility aid ▪ Need prompt action by seating clinic at hospital to avoid long delays in making and adjusting equipment ▪ Need a hospital bed with up and down facilities and cot sides ▪ Need for appropriate sized vehicle to cater for child's equipment and the rest of the family

Appendix 18 **PRACTICAL NEED DOMAIN TIME 2**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	a) Medical equipment	a) for servicing and repair	• Needs medical equipment servicing
DG2	a) Medical equipment b) Transportation c) Intersectorial working	a) opportunity to try equipment before purchasing b) advice on appropriate equipment c) written authority from DSS that child eligible for motability d) equipment for physiotherapy sessions at school e) child to be seen at centre of excellence but difficulty with travelling to tertiary centre f) to learn to drive	• Needs a letter about motability entitlement from DSS to give to local garage • Needs written authority that child is eligible for motability • Needs appropriate equipment at school for physiotherapy sessions • Wants to be seen at a centre of excellence but has difficulty in getting to tertiary centre in London • Needs advice on equipment • Would like the opportunity to try out equipment before buying it • Needs to get transport problems sorted – wants to learn to drive
DG3	a) Medical equipment b) Aids to daily living c) Intersectorial working	a) for symptom control b) help from SS OT re home adaptations c) to have mobility aid repaired	• Needs to know what is happening about aids to daily living and accommodation being organised by DSS OT • Wants to get medical equipment installed properly • Needs to get buggy repaired
	a) Aids to daily living to deal with large scale movements of child (in present and future situation) b) Transportation (for dealing with present and future situation) c) Intersectorial working	a) mobility aids b) help with bathing child c) negotiate with owner re home adaptations d) appropriate vehicle: to avoid lifting child; to accommodate equipment and rest of family	• Feel child needs a headrest for wheelchair while travelling in the car to prevent whiplash: – hospital do not agree • Need an appropriate sized vehicle to accommodate child, equipment and siblings • Wants to be able to discuss with council the necessary adaptations to home to get what he feels is best for family – not just extend size of bathroom • Wants a bigger bathroom and bedroom – adaptations done when child was a baby – no longer suitable now she is bigger • Wants a plinth in bathroom to dress child on • Needs a way of bathing child with hoist without getting excess water everywhere

Appendix 19 **PRACTICAL NEED DOMAIN TIME 3**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	No expressed need coded		
DG2	a) Aids to daily living (present and future situation)	a) to resolve housing difficulty with council - either to move or have an extension approved	• Would like housing situation sorted with council - either to move or get extension approved • Problems with council housing - "you have to get right to the very limit before they do anything for you" i.e. with adapting the home
DG3	a) Medical equipment b) Intersectorial working c) Transportation d) Aids to daily living	a) for symptom control b) confidence to learn to drive c) education services to respond to child's needs with transport to school	• Wants child to have a taxi to school rather than school bus makes the day so long and child is exhausted • Child has difficulty getting onto bus mother wants him to go by taxi • Need help with cramped space and noisy equipment (oxygen concentrator) • Wants the confidence to learn to drive
	a) Aids to daily living	a) adaptations to child's bathroom and bedroom (original adaptations made 10 years ago)	• Would like a larger bedroom and bathroom to accommodate their child • Original adaptations made to house when child was very small - now 10 years old

Appendix 20 SOCIAL NEED DOMAIN TIME 1 (RECRUITMENT INTERVIEW) (CG = CONTROL GROUP)

DG	Higher range of themes	Middle range of themes	Summary of needs from verbatim quotations
	a) Respite care	a) baby-sitter able to administer drug treatments b) to be able to enjoy a break with spouse c) someone to stay with child at short notice (employment difficulties)	▪ Desperate need to get away for a break with spouse ▪ Needs qualified baby sitter to be able to give nebulisers and things ▪ Someone to stay with child at short notice employer difficulties (CG) ▪ A break from each other (mother and child) (CG)
DG2	a) Respite care b) Assistance with daily life c) Help with daily care / treatments	a) to be able to enjoy a break with spouse b) baby-sitter able to deal with an emergency c) time (to be able to do more in house) d) assistance at home while resident in hospital e) assistance with performing therapies at home f) help from extended family to look after children at night g) to have a break during the 'bad' times h) domestic help	▪ Need to be able to do more in the house i e. have more time to do housework ▪ Need for respite confirmed by actually having been away ▪ Need for help with the rest of the family while resident with the ill child ▪ Need for babysitters ▪ Need for suitably qualified / trained babysitter - lay people don't know what to do in an emergency ▪ Non skilled childminding needed when child is well ▪ Would like to get a break but "I'd probably soon miss her though" ▪ Needs a break with spouse ▪ someone to do the ironing (CG) ▪ responsible babysitter able to handle situation (CG) ▪ family members to offer to look after children overnight (CG) ▪ a break during the bad times (CG) ▪ assistance with chores (CG) ▪ a break with spouse (CG) ▪ time alone with spouse (CG)
DG3	a) Respite care b) Help with daily care / treatments	a) care in the home environment b) residential (i.e. SS and hospice) care c) Nursing assistance in the home d) baby sitter able to deal with complexities of situation e) offer of assistance with caring for child at home (won't ask)	▪ More frequent respite care with link carer "it's often enough to keep our heads above water" ▪ A definite need for more link carers ▪ Need for respite care in the home at night ▪ Need for help with undertaking twice daily physio ▪ Need nursing help in the home on occasions when child particularly ill especially during the night ▪ Someone to offer to care for the child and able to deal with complexities – "probably only a nurse would take it on". (CG) ▪ Baby sitting by a specially trained person (CG)
	a) Respite care b) Assistance with daily life	a) baby-sitter able to deal with profoundly disabled b) domestic help	▪ Need for domestic help at home although doesn't feel right to ask for it ▪ Need for suitable baby sitter as reliant on child's grandmother ▪ Definitely would like help with housework "I do mine at 11pm at night" ▪ Would like an alternative source of help for baby sitting other than own mother ▪ Need for appropriate baby sitters young girls not appropriate ▪ Assistance with ironing (CG)

Appendix 21 **SOCIAL NEED DOMAIN TIME 2**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	a) Respite care b) Assistance with daily life	a) care during school holidays b) domestic help	• Would like some domestic help at home • Would like respite care especially in school holidays in the day time (can't go to houses with cats)
	a) Respite care b) Help with daily care / treatments	a) the establishment of overnight stays with link family b) stimulation outside the domestic situation c) the opportunity for a break d) a break from the daily treatments e) Assistance with performing therapy	• Would like to get link family (respite care) overnight established • Would like some stimulation outside the domestic situation • Would like the opportunity to get a break occasionally • Would like a break from day to day treatments • Needs help with performing physiotherapy treatments • Would like practical help with day to day treatments in the home
G	a) Respite care b) Help with daily care / treatments	a) to re-establish contact with day time link carer b) Day time nursing assistance	• Would like to re-establish link carer (respite care) during the daytime • Needs practical nursing help at home at night (respite) when child ill • Needs help at home in the day when child is ill and requiring intensive treatment
	a) Respite care b) Assistance with daily life	a) baby-sitter able to deal with profoundly disabled b) more respite care "as much as possible" c) a reliable baby-sitter in order to attend college d) domestic help e) help at home with the extra work a disabled child brings	• Would like more respite care " as much as possible" • Would like help with domestic / household practicalities • Would like help at home with all the extra bits and pieces having a disabled child brings • Would like more residential respite care • Needs help with babysitting

Appendix 22 **SOCIAL NEED DOMAIN TIME 3**

DG	Higher range themes	Middle range themes	Summary of needs from verbatim quotations
	a) Assistance with daily life	a) domestic help	• No chance to do anything around the house when child acutely ill – regular help would be nice
DG2	a) Respite care	a) a reliable baby-sitter b) a responsible baby-sitter - reluctant to ask friends fearful they won't want responsibility	• Would like to have a reliable person to do babysitting • Need for baby sitter, reluctant to ask friends in case they don't want to
DG3	a) Respite care b) Help with daily care / treatments	a) night assistance when child recovering from acute episode b)nursing assistance someone available at short notice c) night sitter during episodes of acute illness	• Need respite care at night when child is not well and starting to get better • Need respite care in the home a nurse who "doesn't work and is available at short notice" - not a stranger because he won't take to someone he doesn't know • Need nursing assistance at night at home when acutely ill • Needs someone "just to be with him" when poorly or getting over and illness at home.
	a) Respite care	a) baby-sitter or child minding by someone able to deal with profoundly disabled child	• Would like child minding and babysitting not really getting any!

Appendix 23 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: MOBILITY

	r rG p 2	Disorder Group 3	
• Fully mobile	• all bar 1 walk independently in the home • one child walks with calipers and uses wheelchair • not normal walking / running frequent falling over • strategies described to maintain mobility, reduce pain and cramps • noticeable deterioration over 3 interviews with neuro-muscular disorders • slight improvement may be lull before the storm	• no problems except for • 2 children whose limited mobility relates to poor exercise tolerance and breathlessness on exertion • one child has development delay	• no independent mobility • wheelchair bound

Appendix 24 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: EATING AND DRINKING

	ı d r p 2	D sorder Group 3	
• unaided • poor appetite • supervision when eating away from home	• a major cause for concern • poor eaters • constant battles to get children to eat	• a source of difficulty - children need supplements, special diets and have food intolerance's • all except 2 have poor appetites • 1 needs to be fed	• time consuming for all • 1 able to chew and swallow normal food • others fed artificially or with pureed food

Appendix 25 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: ELIMINATING

	D de p 2	Disorder Group 3	
• nocturnal enuresis • bowel problems related to drugs and level of atopy	• all except 2 children with CF have trouble with bladder control	• 1 child doubly incontinent • 1 child nocturnal enuresis and back to wearing nappies • others no problems	• all doubly incontinent • 1 child's bowels controlled with alternate day enemas • others regularly 'toileted'

Appendix 26 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: SKIN / ABILITY TO TURN SELF

	D der p 2	Disorder Group 3	
• eczema • atopic	• child with limited mobility wakes frequently at night to be turned	• no problems reported	• 2 children wriggle a lot and thus 'able' to relieve pressure • 2 require turning at night

Appendix 27 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: MOVING AND HANDLING

	so d r p	Disorder Group 3	
• No problems reported	• No problems reported	• 1 child requires major assistance	• all categorised as '2 man lift' at school but activities in the home which require the child to be moved are generally managed by 1 parent • moving and handling aids: no family had a hoist at the first interview, 2 families had one by the second interview. 2 were still without aids at interview 3 • 2 had bath chairs which lowered the child into the bath

Appendix 28 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: HYGIENE

	r p 2	Disorder Group 3	
• Independent (age related)	• Need some assistance	• 2 children need major assistance • Others require some assistance	• Totally incapable of all aspects of personal hygiene

Appendix 29 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: DRESSING

	er p	Disorder Group 3	
• Independent (age related)	• need some assistance • one mother thinks child is never going to perform these tasks so why bother trying to get child to do it.	• 2 children require major assistance • others can do more than they do – parents don't have time or inclination for child independence	• need to be dressed

Appendix 30 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: SLEEPING

	d r oup 2	Disorder Group 3	
• no problems apart from those with enuresis	• no problems apart from a child who needs turning wakes frequently at night	• a problem for 3 children related to symptoms of their disorder	• 1 child wakes every night wanting comfort and reassurance

Appendix 31 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: COMMUNICATING

	s d r oup 2	Disorder Group 3	
• No problems	• all able to express themselves to family • speech therapy to assist with speech development	• all except 1 have difficulty expressing themselves • 4 children having speech therapy	• 2 children have no methods of communicating needs • other 2 have very limited non verbal communication • all able to express happiness / displeasure

Appendix 32 FACTORS AFFECTING NEED: FUNCTIONAL ABILITY: COGNITIVE ABILITY

	or G o p	D sorder Group 3	
• No cognitive impairment	• No cognitive impairment except for one with slight learning disability	• 3 children have moderate to severe learning disabilities	• Profound learning disabilities

Appendix 33 **FACTORS AFFECTING NEED: CARING INTERVENTIONS: CARING PROCESS**

	D o d G p 2	Disorder Group 3	
• Assessing condition • Monitoring condition during an episode of acute illness • Making a judgement about needing hospital treatment or not • Not following Dr's instructions (frequency of nebulisers, physiotherapy) • Monitoring condition to watch for relapse • Making a judgement about which drug treatment to use • Making a judgement about increasing drug dosages when child has a cold • Knows limits to stick to with drug administration • Assessing effectiveness of drug therapy • Responding to condition ie making decision to administer anti pyretic	• Monitoring child's condition especially when mobile as frequently falls over • Understanding what is happening during an attack • Observing child when taking enzymes • Encouraging child to take responsibility for some of own care Encouraging child to play sports as a form of extra physiotherapy • Involving one or two good friends in child's care • Making a decision about when and with what food child needs enzymes • Assessing condition and making a decision to increase the frequency of physio sessions • Deciding to wait until child desperate with stomach cramps as child doesn't like medicine • Leave the decision to the child when to take medicine to reduce stomach cramps • Decision to keep CF very low key - minimalise the situation • Obtaining information from specialist CF centre - not local hospital • Cut holiday short to get child treated	• Choosing which centre child should attend (local or tertiary centre) • Dealing with child's non compliance with medication • Deciding to be strict with administration of drugs to aid compliance • Observation of condition • Assessing effectiveness of drug treatment • Monitoring child's condition (for relapse of condition) • Monitoring child's development (growth) (potential drug side effects) • Informing child's carers (professionals and voluntary) about life-threatening symptoms • Decides when to administer antibiotics at home (rather than visit GP)	• Making a judgement as to when to administer oxygen ie when chesty or having a seizure • Making a decision about child wearing her brace with a pressure sore on her hip • Making a judgement about taking child to hospital for intervention with a seizure if agreed protocol doesn't work at home • Allowing child to cough and clear secretions rather than frequent suctioning of trachy • Making a judgement about the administration of rectal drugs for seizure

Appendix 34 **FACTORS AFFECTING NEED: CARING INTERVENTIONS: PRACTICAL INTERVENTIONS EXCEEDING NORMAL PARENTING RESPONSIBILITIES**

	o G p 2	Disorder Group 3	
• Administration of complementary medicine • Administration of oral drugs • Administration of drugs via Inhalers and spacer device • Administration of drugs via nebuliser • Administration of oral chemotherapy • Maintaining patency of Hickman line • Blood sampling from Hickman line Weekly blood sampling (finger prick) • Maintenance of emergency drug pack at home • Maintenance of emergency drug pack at school	• Turning the child at night (2, 3, or 4 times is normal) • Administration of asthma drugs via an inhaler • Limb and standing exercises • Speech therapy exercises • Application of night splints • Massaging legs to keep them soft under night splints • Administration of PR drugs to reduce severity of attack • Administration of oral drugs • Setting up and administering enteral feed via pump • Preparing enzymes for child to take to school • Twice daily physiotherapy - sessions tipping and clapping, Twice daily physiotherapy - forced expiratory technique • Administration of DNase via nebuliser • Administration of antibiotics via nebuliser • Keeping medical equipment clean and in working order • Sterilising equipment for enteral feeding • Maintenance and trouble shooting problems with gastrostomy tube • Administration of prophylactic antibiotics • Administration of enzymes with food and snacks • Using towels on physiotherapy tipping table to avoid covers getting soiled • Recent visit from physiotherapist to teach new techniques • Three - four times daily physiotherapy when child has a cold • Administration of nasal spray • Administration of drugs to treat mucous build up in the stomach • Midnight physiotherapy Tendon stretching exercises • Physiotherapy sessions in the local swimming pool • Massaging and stretching exercises to dispel night muscle cramps • Taking children for speech therapy appointments	• Administration of asthma drugs via inhaler • Administration of dietary supplements • Administration of oral drugs • Use of protocol developed by asthma nurse as guidelines for administration of treatments • Application / maintenance of apnoea monitor sensor • Use and maintenance of complicated medical equipment to monitor condition • Respond to child having apnoeic spell i.e. varying degrees of resuscitation methods • Administration of drugs via nebuliser • Administration of night sedation • Administration of oxygen at night • Urinalysis twice daily • Responding to child having 'blackout' • Holistic limb exercises • Encouraging child to practice speech therapy exercises	• Carry child upstairs • Lifting child to car, upstairs into bath • Maintenance of medical equipment • Administration of oxygen suctioning tracheostomy tube • Administration of rectal drugs for seizures • Administration of oral drugs • Administration of vitamin supplements • Feeding child pureed food • Application of spinal support brace • Application of dressing to pressure sore on hip • Purchase of dry dressings for hip • Administration of alternate day enema's • Feeding child regular meals to avoid fits • Changing nappies • Dressing child • Bathing child • Administration of bolus feeds via gastrostomy tube • Offering small amounts of food to keep mouth moist • Administration of drugs via gastrostomy tube • Lifting child into sling to bathe child

Appendix 35 FACTORS AFFECTING NEED: CARING INTERVENTIONS: ADDITIONAL CARING BURDEN

• Carrying emergency drug pack at all times • Extreme care taken to avoid exposure to allergens	• A battle with eating which takes an enormous amount of time • Two battles a day with physiotherapy • Carry child when gets leg cramps • Massaging away muscle cramps during the night	• The administration of dietary supplements ('just another job for us to do') • Up at night with child • Child needs watching like a 2 year old but is very much bigger	• Up in the night to check on child Child needs constant care • Application of too small brace as surgery imminent "basically I've got to persevere with this" • Very tiring caring fore child all the time

Appendix 36 FACTORS AFFECTING NEED: CARING INTERVENTIONS: PARENTAL SHARING THE ADDITIONAL CARING RESPONSIBILITIES

• Father home from work at 4pm – mother then goes to work so as not to worry about other people looking after children • Father does some practical caring tasks but mother feels burden is still on her	• tendon stretching exercises	• Dad helping to get child up and ready for school	• Father helps with heavy lifting sometimes when he is around

Appendix 37 FACTORS AFFECTING NEED: CARING INTERVENTIONS: ADDITIONAL CARING BURDEN ON MOTHER

• Mother attends parties and takes own food to avoid accidental exposure to allergens • Responsibility for night nebulisers • Attending to the child in the night Worry - watching and waiting to see how bad they get • Monitoring condition • Assessing condition • Difficulty with administration of oral drugs – hold child down	• Turning child at night 3 or 4 times "it's a broken nights' sleep" • Child wakes more frequently at night than when she was a baby • Child doesn't want dad to get up in the night • Mother takes child out of main stream school once a week to attend physio dept at special school • Difficulty with physiotherapy as child struggles • Not worth the bother of going out - care is time consuming • Physiotherapy sessions - "physically exhausting and mentally exhausting because she hates it and I hate it"	• Medical equipment needing to be plugged in - battery lasts for short time so mum had to get other children to school in that short space of time • Having to restrain child to administer drugs • Having to deal with child's behaviour problems (drug side effects) • Up in the night with child (child refuses Dad) • Time consuming doing 3 hourly nebulisers throughout day • Up and down stairs at night replacing oxygen cannulae	• Lifting child as child is heavy burden on father (principal carer) doesn't want mother to do it • 2 man lift at school but mum lifts child at home on her own • Fighting the system (school) and feeling very pressurised • Feels pressurised by therapists to do physio herself • Lifting child as father not around during day • Lifting child from bath to • (Father in this group)

Appendix 38 FACTORS AFFECTING NEED: CARING INTERVENTIONS: Coping with additional demands of practical interventions

	der G up 2	Disorder Group 3	
• Managing child's non compliance with inhaled drugs • Learning how to administer emergency injection • Improving child's technique with inhaler • Encouraging child to take medicines which he doesn't like • Remembering and dealing with complex drug regime	• Fund-raising to buy electric wheelchair • Open post office account for fund raising • Ways of making sure child has enzymes prior to food (sprinkled on yoghurt) (on food, in drink,with a straw, on a spoon, syringe without a needle, pellets in bananas, bribery with lego) (open capsule onto a spoon, bribery with chocolate) • Reducing child's anxiety (telling him that hopefully he won't need physio soon)	• ways of getting child to take drugs • Finding best time for child to have oral drugs to minimise side effects • Trying to get child to sit still to counter balance drug side effects • Use of daily diary / calendar to record differing daily drug regime	• None

Appendix 39 FACTORS AFFECTING NEED: CARING INTERVENTIONS: DEVELOPING EXPERTISE WITH PECULIARITIES OF ILLNESS

	s p 2	Disorder Group 3	
• "get a feeling" with assessing condition and evaluating home treatment • "we can usually tell" if it is going to be a full blown attack • Evaluating condition • Assessing the severity of an attack and responding with appropriate drug treatment • "not so nervy now" about side effects with administration of steroids	• "Didn't like the look of her" - mother knew child needed treatment while on holiday • Mother uses her previous knowledge to challenge the treatment prescribed by the Dr. • Mother has learnt that she can reduce the severity of an attack with the administration of antipyretic drugs • An increased number of physiotherapy sessions cures chesty coughs • The need for a midnight physiotherapy session "when you've lived with the child for 2.5 years you get a feel for things"	• 'I'm aware now when I get tired everybody suffers for it'. (doing 3 hourly nebs) • Mother knows when child is going to relapse	• "You've got to be alert and have your ear • trained for the least danger sign when your child's got a tracheostomy" • The potential difficulties with trachy site care and avoiding problems • Child has seizures prior to illness • Gives saline into trachy prior to feeding to clear her to avoid coughing through mealtimes • Knows child needs a lot of suction at meal times and before bed • Knows child swallows food into lungs so uses gastrostomy tube for main calories

Appendix 40 FACTORS AFFECTING NEED: CARING INTERVENTIONS: MANAGING COMPETING DEMANDS OF TWO AFFECTED CHILDREN

	s r p 2	Disorder Group 3	
• Juggle one nebuliser between two children. – purchase of second nubuliser • Makes lists of drugs to avoid confusion with drugs and dosages Duration of attack doubles, as one child finishes the other starts • Differences in drug management between two children	• With physiotherapy sessions in swimming pool mother looks after one child and the physiotherapist looks after the other	• None recorded	• None recorded

Appendix 41 FACTORS AFFECTING NEED: CARING INTERVENTIONS: ADDITIONAL PARENTAL CONCERNS WITH CARING FOR A CHILD

	D o er ro p 2	Disorder Group 3	
• Giving an injection of adrenaline under stressful conditions • Teaching anaphylaxis training to school "out of my league" • Doesn't want child to have responsibility for emergency adrenaline pack • Wants child to be supervised if should need to take adrenaline at school • Should do physio but can't remember if it should be before or after nebuliser	• Has recently changed enzymes for weaker strength but stronger suited him better - would like these back • Wonders if doing physio correctly would like up to date teaching on techniques • Wary of treatment child received while on holiday abroad • Would like portable nebuliser to avoid a reoccurrence of problems while on holiday • Worries about how will cope when child goes to school to get all treatment done in the morning • Worries about needing to go into school all the time in the winter to do physiotherapy • Worries about the child's need for an operation in the future • Trying to find out appropriate drug dosages from book	• Worrying about asking for disposable medical items needed for equipment • Wants information about drugs and their side effects • Difficulties with large piece of medical equipment in small house • Angry with previous hospital consultant for not admitting he didn't know • Uncertainty about future drug regime • Worried about integrating child into local community from a learning disability point of view	• Being careful and caring for the trachy site • Worries about lack of assistance for child at school • Feeling swamped with professionals "it is quite overwhelming" • Lack of therapy services • feels pressurised by professionals not able to say not happy to professionals • Dislike of patronising professionals • Sling used for bathing gets bedroom very wet

Appendix 42 FACTORS AFFECTING NEED: CARING INTERVENTIONS: CO-ORDINATION ROLE

	so d r Gr up 2	Disorder Group 3	
• Liaison with GP with change of medical management instructions from hospital • Ask advice from GP before admin of drugs in an attack • Liaison with hospital if home treatment not effective • Finding out details of syringes and needles for emergency drug administration for local pharmacist • Liaison with asthma nurse re non-compliance problems	• Mother telephone's clinic in London when child outgrown callipers • Liaison with physiotherapist who checks child at school • Organise own equipment swap with local CF charity • Liaise with school staff about child's need for physiotherapy • Gave a teaching session to the school to "show them what it involves" • Liaison with the hospital for equipment • School informs mother when child out of enzymes for school lunch • Mother liaises with teachers each year to explain situation • Asks advice from specialist CF centre • Liaison with physiotherapist to recommence sessions	• With hospital ward to obtain disposable medical supplies • With GP about medical equipment 'so that he could help us with it' • With hospital doctors to reduce asthma treatment • With nursery school about drugs and side effects and management With GP about child's behaviour being related to drugs • With hospital doctors regarding a need for symptom control i.e. oxygen tent • With hospital doctors to start treatment for relapse • With local community who come in and help with exercise routines • With GP for antibiotics	• Taking suction equipment to hospital for repair • With community hospital for requisition for equipment repair • With charity regarding loan of medical equipment • With primary health care team regarding disposable supplies • With hospital doctors re amount of drug needed to control seizures

Bibliography

ACT Charter (1993) Association for children with life-threatening & terminal conditions & their families, Bristol.

ACT & Royal College of Paediatrics & Child Health (1997) A Guide to the Development of Children's Palliative Care Services Report of a Joint Working Party. ACT & RCPCH, London.

Anderson N and Crawforth M (1995); All in the family: siblings and disability NCH Action for Children, London.

Andrews M & Nielson D (1988) Technology dependent children in the home. Pediatric Nursing 14 (2) 111-114.

Anon (1983) On children dying well The Lancet 30 April 1966.

Appleton P, Boll V, Everett J, Kelly A, Meredith K, Payne T (1997) Beyond child development centres: care co-ordination for children with disabilities. Child: Care, Health & Development 23 (1) 29-40.

Atwell JD & Gow MA (1985) Paediatric district nurse in the community: expensive luxury or economic necessity BMJ 291 227-229.

Audit Commission. (1993) Children First: A study of hospital services. HMSO, London.

Audit Commission (1994) Seen but not heard: Co-ordinating community child health and social services for children in need. HMSO, London.

Baine S, Rosenbaum P, King S (1995) Chronic childhood illnesses: What aspects of caregiving do parents value? Child: Care, Health and Development 21 (5) 291-304.

Baldwin S (1985) The cost of caring: families and disabled children. Routledge & Kegan Paul, London.

Baldwin S & Carlisle J (1994) Social support for disabled children their families: a review of the Literature. Action for Sick Children, London.

Baum J D (1990) In Baum JD, Sr Dominica F & Woodward RN (1990) (Eds) *Listen my child has a lot of living to do*, Oxford University Press, Oxford.

Baum J D (1994) Introduction: the magnitude of the problem. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

Bell J (1987) Doing your research project Open University Press, Milton Keynes.

Bendefy I M (1991) Home nebulisers in childhood asthma: survey of hospital use. British Medical Journal 302:1180-1181.

Beresford (1993) Easing the strain: assessing the impact of a Family Fund grant on mothers caring for a severely disabled child. Child: Care, Health and Development 19. 369-378.

Beresford B (1994) Positively parents: caring for a severely disabled child. York: Social Policy Research Unit, University of York.

Beresford B (1995) Expert Opinions: A survey of Parents Caring for a Severely Disabled Child. The Policy Press, Bristol.

Beresford B, Sloper P, Baldwin S, Newman T, (1996) What works in services for families with a Disabled Child. Barnardo's, Ilford.

Betts C & Meyer G (1993) Children with Disabilities. In Glasper E & Tucker A (Eds) Advances in Child Health Nursing. Scutari Press, Harrow.

Betz C, Unger O, Frager B, Test L & Smith C (1990) A survey of self help groups in California for parents of children with chronic conditions. Pediatric Nursing 16(3) 293-296.

Birch J M, Marsden H B, Morris Jones P H, Pearson D & Blair V (1988) Improvements in survival from childhood cancer: results of a population based survey over 30 years. British Medical Journal. 296. 1372-1376.

Black D (1994) Bereavement. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

Bodkin C M, Pigott t J, & Mann J R (1982) Financial burden of childhood cancer. British Medical Journal. 284. 1542-1544.

Botting B (1995) (Ed) The health of our children: decennial supplement OPCS DS11 HMSO London.

Bowlby J (1953) Child care and the growth of love. Pelican, Harmondsworth.

Bowling A (1996) Health care rationing: the public's debate, British Medical Journal 312 670-674.

Bradford R (1997) Children, Families and Chronic Disease: Psychological models and methods of care. Routledge, London & New York.

Bradley C (1993) Designing medical and educational intervention studies. Diabetes care 16 509-518.

Breyer J, Kunin H, Kalish L & Farkas Patenaude A (1993) The adjustment of siblings of paediatric cancer patients -a sibling and parent perspective, Psycho-Oncology 2 201-208.

Broadbent V (1987) Hospices for Children? Letter British Medical Journal 294 1548.

Brown A & Hepple S (1989) How Parents Cope: Caring for a child who has a handicap. Barnardo's, Ilford.

Bryman A (1988) Quantity and Quality in Social Research. Routledge, London.

Burne R (1982) Helen House - a hospice for children. Health Visitor 55(10). 544-545.

Burne R (1988) Terminal care in children. Maternal and Child Health. 13(10).284-287.

Burne R (1994) Progressive degenerative diseases. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, London.

Burne S R, Dominica F, & Baum J D (1984) Helen Hospice - a hospice for children: An analysis of the first year. British Medical Journal 289(6459). 1665-1668.

Burney P, Chinn S & Rona R (1990) Has the prevalence of asthma increased in children? Evidence from the national survey of health and growth 1973-1986 British Medical Journal 300 1306-1310.

Burns C E & Madian N (1992) Experiences with a support group for grandparents of children with disabilities. Pediatric Nursing. 18(1).17-21.

Burns N & Grove S (1993) The practice of nursing research. Conduct, critique and utilization 2nd edition. WB Saunders Company, Philadelphia.

Burr C (1985) Impact on the family of a chronically ill child. In Hobbs N & Perrin J (Eds) Issues in the care of children with chronic illness. Jossey-Bass Inc., San Francisco.

Burr S (1997) Annex 1 In House of Commons Health services for children and young people in the community. Third report of the health committee. Chair. Mrs Marion Roe. Stationary Office London.

Burton L (Ed) (1975) The Family Life of Sick Children. Routledge and Kegan Paul, London.

CF Trust (1993) Finding out about CF. CF Trust Bromley, Kent.

Cairns N, Clark G, Smith S & Lansky S (1979) Adaptation of siblings to childhood malignancy, The Journal of Pediatrics 95 (3) 484-487.

Cambridgeshire LEA (1995) Medication in schools policy, Cambridgeshire County Council, Cambridge.

Canam C (1993) Common adaptive tasks facing parents of children with chronic conditions, Journal of Advanced Nursing 18 46-53.

Carers (Recognition and Services) Act (1995) HMSO, London.

Casey A (1988) Partnership with child and family. Senior Nurse 8 (4) 8-9.

Casey A (1993) Development and use of the partnership model of nursing care. In Glasper E & Tucker A (Eds) Advances in Child Health Nursing. Scutari Press, Harrow.

Chambers E J, Oakhill A, Cornish J M, & Curnick S (1989) Terminal care at home for children with cancer. British Medical Journal 98 937-940.

Chambers T L (1987) Hospices for children? (Editorial) British Medical Journal 294 1309.

Charlton T & Macaulay M (1993) Good Communication heralds successful integration. Professional Nurse 8 (9) 600-602.

Children Act (1989). HMSO, London.

Childs H & Dezateux C (1991) A national survey of nebulizer use. Archives of Disease in Childhood 66 1351-1353.

Clare L & Pistrang N (1995) Parents' perceptions of portage: Towards a standard measure of parent satisfaction. British Journal of Learning Disabilities 23 110-117.

Cleary B (Ed) (1990) The Rainbow Trust: A domicillary crisis service. In Baum JD, Snr Dominica F and Woodward RN (Eds) Listen, My child Has A Lot Of Living To Do. Oxford University Press, Oxford.

Cleary J, Gray O P, Hall D J, Rowlandson P H, Sainsbury C P Q & Davies M M (1986) Parental involvement in the lives of children in hospital. Archives of Disease in Childhood. 61 779-787.

Closs A & Burnett A (1995) Education for children with poor prognosis: reflections on parental wishes and on appropriate curriculum. Child: Care, health and Development 21 (6) 387-394.

Cohen M (1995) The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. Qualitative Health Research 5 (1) 63-77.

Cole R (1994) Providing Family Respite. Nursing Times 90 (28) 15.

Contact A Family (1991) The CAF Directory of specific conditions and rare syndromes in children with their family support networks. Contact-a-Family, London.

Cook T & Campbell D (1979) Quasi-experimentation design and analysis. Issues for field settings. Houghton Mifflin Company, Boston.

Cornish J, While A, Citrone, C (1996) The contribution of voluntary organisations to the care of children with life-limiting incurable disorders and their families. Children and Society 10 280-292.

Cottrell D & Summers K (1990) Communicating an evolutionary diagnosis of disability to parents Child: Care, Health and Development 16 211-218.

Cox D & Parish A (1989) Working in Partnership: Themes and issues. Barnardo's, Ilford.

Cowper D & Lenton S (1996) Letter writing to parents following paediatric outpatient consultation: A survey of parents and GP views. Child: Care, Health and Development 22 303-310.

Coyne I T (1995) Parental participation in care: a critical review of the literature. Journal of Advanced Nursing. 21. 716-722.

Coyne IT (1997) Chronic Illness: the importance of support for families caring for a child with cystic fibrosis. Journal of Clinical Nursing 6 121-129.

Curnick S (1990) Domicillary nursing care. In Baum J D, Sr. Dominica F and Woodward R N (Eds) Listen, My Child has A Lot Of Living To do. Oxford University Press, Oxford.

Dale N (1996) Working with families of children with special needs: Partnership and practice. Routledge, London & New York.

Darbyshire P (1994) Parenting in Public: Parental participation and involvement in the care of their hospitalised child. In Benner P (Ed) Interpretive Phenomenology . Sage, Thousand Oaks CA.

Davis H (1993) Counselling parents of children with chronic illness or disability. The British Psychology Society, Leicester.

Davies RE (1998) The growth of hospices in the UK. Paediatric Nursing 10 (8) 23-26.

Day S (1990) Acorns. In Baum J D, Sr. Dominica F & Woodward R N (Eds) Listen, My Child has A Lot Of Living To do. Oxford University Press, Oxford.

de Rome C & Sykes A (1995) Personal communication. Lifespan Healthcare NHS Trust, Cambridge.

Dearmun A (1992) Perceptions of parental participation. Paediatric Nursing 4 (7) 6-9.

Department of Health (1991) The Welfare of Children and Young People in Hospital. HMSO, London.

Department of Health (1992) Press Release - William Waldegrave announces £5million programme to help children with life-threatening illness. Department of Health, London.

Department of Health (1996) The Patient's Charter Services for Children and Young People. HMSO, London.

Department of Health (1997) Government Response to the Reports of the Health Committee on Health Services for Children and Young People. CM 3793. Stationery Office, London.

Department of Health and Social Security (1976) Fit for the Future. The Report of the Committee on Child Health Services. Cmnd. 6684. (Chairman: Professor SDM Court). HMSO, London.

Dominica F (1982) Helen House - A hospice for children. Maternal and Child Health. 7(9). 355-359.

Dominica F (1987) Guest editorial. Journal of Advanced Nursing. 12 149 - 150.

Dominica F (1990a) The way forward. In Baum JD, Sr Dominica F & Woodward R N (Eds) Listen, My Child has A Lot Of Living To do. Oxford University Press, Oxford.

Dominica F (1990b) Hospices: a philosophy of care. In Baum JD, Sr Dominica F & Woodward R N (Eds) Listen, My Child has A Lot Of Living To do. Oxford University Press, Oxford.

Dominica Sr F & Hunt A (1993) Children's Hospices. In Glasper E & Tucker A (Eds) Advances in Child Health Nursing, Scutari Press, Harrow.

Draper G (1995) Cancer. In Botting B (Ed) The health of our children HMSO, London.

Drotar D & Crawford P (1985) Psychological adaptation of siblings of chronically ill children: Research and practice implications. Developmental and Behavioural Pediatrics 6 (6) 355-362.

Dryden S (1986) Paediatric nursing: home healing. Community Outlook 8, 25-26.

Dryden S (1989a) Care in the community. Paediatric Nursing 1 (7) 19-20.

Dryden S (1989b) Paediatric medicine in the community. Paediatric Nursing 1 (8) 17-18.

Duce S (1999) Personal communication Royal Brompton & Harefield NHS Trust, London.

Duncan C & O'Flynn C (1995) The CHIPPS Project: Children at home, in partnership with parents report. Mid-Anglia Community Health Trust, Suffolk.

Dunst C, Trivette C, Deal A (1994) Enabling and empowering families: Principles and guidelines for practice. Brookline Books, Cambridge MA.

Eaton N & Thomas P (1998) Community Children's Nursing: an evaluative framework. Journal of Child Health Care 2 (4) 170-173.

Editorial (1994) Paediatric community nursing: does it really save money? At Home 7.5.

Education Act (1993) HMSO, London.

Edwardson S (1983) The choice between hospital and home care for terminally ill children. Nursing Research 32 29-34.

Eiser C (1990) Chronic Childhood Disease. An introduction to psychological theory and research. Cambridge University Press, Cambridge.

Eiser C (1993) Growing up with a chronic disease: The impact on children and their families. Jessica Kingsley, London.

Eiser C (1994) Making sense of chronic disease. The Eleventh Jack Tizard Memorial Lecture. Journal of Child Psychology and Psychiatry 35 (8) 1373-1389.

Eiser C & Havermans T (1992) Mothers' and Fathers' coping with chronic childhood disease. Psychology and Health 7 249-257.

Evans M (1993) Paediatric oncology. In Glasper E & Tucker A (Eds) Advances in Child Health Nursing, Scutari Press, Harrow.

Evans M & Thompson A (1998) The role of the Macmillan Paediatric Nursing Service In Glasper E & Lowdon S (Eds) Innovation in Paediatric ambulatory care. Macmillan, London.

Ewan P (1996) Clinical study of peanut and nut allergy in 62 consecutive patients: new features and associations. British Medical Journal 312 1074-1078.

Farrell M (1992) Partnership in care: paediatric nursing model. British Journal of Nursing 1 (4) 175-176.

Farrell M (1996) The role of a children's hospice. Paediatric Nursing 8 (4) 6-8.

Farrell M & Allen S (1998) Hospice at Home: our first year. Paediatric Nursing 10 (7) 18-20.

Faulkner A (1998) ABC of Palliative Care. Communication with patients, families, and other professionals. British Medical Journal 346 130-132.

Florian V & Krulik T (1991) Loneliness and social support of mothers of chronically ill children. Social Science and Medicine. 32 (11). 1291-1296.

Fradd E (1990) Setting up a paediatric community nursing service. Senior Nurse 10 (7) 4-7.

Fradd E (1992) Working with specialists. Community Outlook 2(6) 29-30.

Gibson C (1995) The process of empowerment in mothers of chronically ill children. Journal of Advanced Nursing 21 1201-1210.

Glaser B & Strauss A (1967) The discovery of grounded theory: strategies for qualitative research. Aldine, Chicago.

Glasper E (1990) Emancipation of parents. Nursing Standard 4 (22) 55.

Glendinning C (1990) The costs of informal care: Looking inside the household. HMSO, London.

Goddard M (1990) Pounds Shillings and Death. Health Service Journal 8 March 364.

Goddard M (1991) Economics of cancer care. Newsletter for the Centre for Health economics. Issue No. 8. University of York.

Goldman A (1990) Domicilary system control. In Baum J D, Dominica F, & Woodward RN (Eds) Listen, My Child Has Got A Lot Of Living To Do. Oxford University Press, Oxford.

Goldman A (1994) Malignant disease. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

Goldman A (1998) ABC of Palliative Care. Special problems of children. British Medical Journal 346 49-52.

Goldman A & Baum D (1994) Provision of care. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

Goldman A, Beardsmore S & Hunt J (1990) Palliative care for children with cancer - home, hospital or hospice? Archives of Disease in Childhood. 65 641-643.

Goldman A & Burne R (1994) Symptom management. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

Gortmaker S (1985) Demography of chronic childhood diseases. In Hobbs N & Perrin J (Eds) Issues in the care of children with chronic illness. Jossey-Bass Inc, San Francisco.

Gow P & Ridgway G (1993) The development of a paedriatic community service. In Glasper E; Tucker A (Eds) Advances in Child Health Nursing. Scutari Press, Harrow.

Gow M & Campbell S (1996) Paediatric Community Nursing: doctors' views. Professional Nurse 11 (6) 365-367.

Gravelle A (1997) Caring for a child with a progressive illness during the complex chronic phase: parents' experience of facing adversity. Journal of Advanced Nursing 25 738-745.

Green J & Britten N (1998) Qualitative research and evidence based medicine. British Medical Journal 316 1230-1232.

Green J M & Murton F E (1993) Duchenne Muscular Dystrophy: the experiences of 158 families. Centre for Family Research, University of Cambridge.

Green J & Murton F (1996) Diagnosis of Duchenne muscular dystrophy: parents' experiences and satisfaction. Child: Care, Health and Development 22 (2) 113-128.

Greenberg L, Jewett L, Gluck R, Champion L, Leikin L, Altieri M & Lipnick R (1984) Giving information for a life-threatening diagnosis, American Journal of Diseases in Childhood 138 649-653.

Hagen O (1990) The Alder Centre: counselling for all those affected by the death of a child. In Baum J D, Sr. Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Halliday J (1990) Malignant disease in children: the view of the general practitioner and parent. In Baum J D, Sr. Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Hally M, Holohon A, Jackson R, Ready B, Walker J (1977) Paediatric home nursing scheme in Gateshead British Medical Journal 1 762-764.

Havermans T & Eiser C (1994) Siblings of a child with cancer. Child: care health and development. 20 309-322.

Heggarty H (1994) Good beginnings. In Hill L (Ed) Caring for Dying Children and their Families. Chapman & Hall, London.

Henderson J, Goldacre M, Fairweather J, Marcovitch H (1992) Conditions accounting for substantial time spent in hospital in children aged 1-14 years. Archives of Disease in Childhood 67 83-86.

Herd E (1990) Helen House. In Baum J D, Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Hill L (1990) Martin House. In Baum J D, Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Hill L (1994) The role of the children's hospice. In Hill L (Ed) Caring for Dying Children and their Families. Chapman & Hall, London.

Hinds C (1985) The needs of families who care for patients with cancer at home: are we meeting them? Journal of Advanced Nursing. 10 575-581.

Hobbs N & Perrin J (Eds) (1985) Issues in the care of children with chronic illnesses. Jossey-Bass Inc, San Francisco.

House of Commons (1997) Health Services for Children and Young People in the Community. Third Report of the Health Committee. Chair: Mrs Marion Roe. London: Stationery Office.

Howard M (1995) Under five and underpaid: the mobility related costs of disabled children under five. Health Visitor. 68 (1) 36.

Hunt JA (1995) The Paediatric oncology community nurse specialist: the influence of employment, location and funders on models of practice. Journal of Advanced Nursing 22, 126-133.

Jeffrey P (1990) Enhancing their lives: a challenge for education. In Baum JD; Dominica F; Woodward RN (Eds) Listen, my child has a lot of living to do. Oxford University Press, Oxford.

Jennings P (1994) Learning through experience: an evaluation of children's community nursing. Journal of Advanced Nursing 19, 905-911.

Jerrett M D (1994) Parents' experience of coming to know the care of a chronically ill child. Journal of Advanced Nursing. 19. 1050-1056.

Joffe H & Vegoda H (1990) Children with life threatening congenital heart disease. In Baum J D, Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Jolly J (1981) The Other Side of Paediatrics. Macmillan, London.

Jordan S & Scott O (1989) Heart disease in paediatrics (3rd ed) Butterworths, London.

Kagan C, Lewis S, Heaton P (1998) Combining work and care: working parents of disabled children. Findings. Joseph Rowntree Foundation, York.

Kelly P (1998) The role of the community children's nurse in enhancing the primary-secondary care interface. In Glasper E & Lowdon S (Eds) Innovation in Paediatric ambulatory care. Macmillan, London.

Kendrick R (1993) Night school, Nursing Times 89 (30) 44-45.

Kirk S (1998) Families' experiences of caring at home for a technology-dependent child: a review of the Literature - Child: care, health and development 24 (2) 101-114.

Kohler J A & Radford M (1985) Terminal care for children dying of cancer: quantity and quality of life. British Medical Journal. 291 115-116.

Koocher G P & O'Malley J E (1981) The Damocles Syndrome: Psychosocial consequences of surviving childhood cancer. McGraw-Hill, New York.

Krulik T (1980) Successful normalising tactics of parents of chronically ill children. Journal of Advanced Nursing. 5. 573-578.

Lavelle J (1994) Education and the sick child. In Hill L (Ed) Caring for Dying Children and their Families. Chapman & Hall, London.

Lavery C (1990) The Society for Mucopolysaccharide Disease and parent self-help groups. In Baum J D, Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Lavinge J V & Ryan M (1979) Psychological adjustment of siblings of children with chronic illness. Pediatrics. 63. 616-627.

Lazarus R & Folkman S (1984) Coping and adaptation. In Gentry W (Ed) Handbook of behavioural medicine. The Guildford Press, New York.

Lessing D & Tatman MA (1991) Paediatric home care in the 1990s. Archives of Disease in Childhood 66, 994-996.

Lightwood R, Brimblecombe F S W, Reinhold J D L, Bunard E D, & Davis J A (1957) A London trial of home care for sick children. Lancet. i. 313-316.

Linker K A (1982) Evaluating Health Visiting Practice: an experimental study to evaluate the effects of focused health visitor intervention on elderly women living alone at home. Royal College of Nursing, London.

Lobato D, Faust D & Spirito A (1988) Examining the effects of chronic disease and disability on children's sibling relationships. Journal of Pediatric Psychology. 13(3). 389-407.

Martinson I, Armstrong G, Geis D, Anglim M, Gronseth E, MacInnis H, Kersey J, Nesbit M (1978) Home care for children dying of cancer. Pediatrics 62 (1) 106-113.

Martinson I, Gilliss C, Colaizzo D, Freeman M & Bossert E (1990) Impact of childhood cancer on healthy school-age siblings, Cancer nursing_13 (3) 183-190.

Maynard L (1993) Organ transplantation psychosocial issues. Paediatric Nursing 5 (10) 20-22.

Maynard L (1994) Paediatric heart and lung transplantation for cystic fibrosis. Heart and Lung 23 (4) 279-284.

Maynard L, Barclay S, Palmer R, Todd C, Vickers D (1996) Families in need: The needs of families caring for children with life-threatening illnesses. Lifespan Healthcare NHS Trust, Cambridge.

Mayo E (1949) The social problems of an industrial civilisation. Routledge, London.

McConachie H (1991) Home based teaching: what are we asking of parents? Child: care, health and development. 17 123-136.

McConachie H (1994) Implications of a model of stress and coping for services to families of young disabled children. Child: Care, Health and Development 20 37-46.

McCubbin H, McCubbin M, Patterson J, Cauble A, Wilson L, Warwick W (1983) CHIP - Coping Health Inventory for Parents: An assessment of parental coping patterns in the care of the chronically ill child. Journal of Marriage and the Family 359-370.

McCubbin H, Thompson A & McCubbin M (1996) Family assessment: Resiliency, coping and adaptation. Inventories for research and practice. University of Wisconsin Publishers, Maddison.

Macfarlane A (1992) Personal child health records' held by parents. Archives of Disease in Childhood 67 571-572.

Meltzer H, Smyth M & Robus N (1989) Disabled children: services, transport and education. OPCS Surveys of Disability in Great Britain; Report 6. HMSO, London.

Middence K, Fuggle P & Davies S (1993) Psychosocial aspects of sickle cell disease (SCD) in childhood and adolescence : A review, British Journal of Clinical Psychology. 32 271-280.

Mikkelsen J (1993a) Sibling care: An attempt to reduce the trauma to siblings of children with life-threatening illness, 1st International Paediatric Nursing Conference Churchill College, Cambridge.

Mikkelsen J (1993b) Sibling care, In Glasper EA and Tucker A (Eds) Advances in child health nursing Scutari Press, Harrow.

Miles M B (1979) Qualitative data as an attractive nuisance: The problem of analysis. Administrative Science Quarterly 24 590-601.

Miles M B & Huberman M (1994) Qualitative data Analysis: an expanded source book. Sage, London.

Millar B (1990) Refuge and respite. Nursing Times 86 (39) 16-17.

Ministry of Health (1959) The Welfare of Children in Hospital. (Chairman: Sir H Platt). HMSO, London.

Morse J & Field P (1996) Nursing research. The application of qualitative approaches (2nd Ed) Chapman & Hall, London.

NHS and Community Care Act (1990). HMSO, London.

NHS Executive (1996) Child Health in the Community: a guide to good practice. Department of Health, London.

NHS Executive (1998) Diana Children's Community Nursing Teams HS circular 1998/201.

NHS Executive (1998) Evaluation of the Pilot Project Programme for Children with Life-Threatening Illnesses. Department of Health, London.

National Association Health Authorities (1988) Care of Dying Children and their Families. NAHA, Birmingham.

Neale T (1990) A social work service for cystic fibrosis families. In Baum J D, Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Neil S & Muir J (1997) Educating the new community children's nurses: challenges and opportunities. Nurse Education Today 17 7-15.

Nethercott S (1993) A concept for all the family. Family centred care: a concept analysis. Professional Nurse 8 (12) 794-797.

Norman R & Bennett M (1986) Care of the dying child at home: a unique co-operative relationship. The Australian journal of Advanced Nursing. 3(4) 3-16.

North Hampshire Loddon Community NHS Trust (1997) Annex 3 III CCN cost breakdown . In House of Commons Health services for children and

young people in the community. Third report of the health committee. Chair. Mrs Marion Roe. Stationary Office, London.

Noyes R (1996) personal communication Lifespan Healthcare NHS Trust, Cambridge.

Nursing Standard Reports (1996) Community child care: a study. Nursing Standard 10 (25) 32.

OPCS (1990) Mortality statisitics, series DH6 No.4 HMSO, London.

Oakley A (1996) Who's afraid of the randomised controlled trial? The challenge of evaluating the potential of social interventions. In what works? Effective Social Interventions in Child Welfare. Barnardo's, Ilford.

O'Neill B & Rodway A (1998) ABC of palliative care. Care in the community. British Medical Journal 346 373-377.

Oppe T (1971) Home care for sick children. British Journal of Hospital Medicine January 39-44.

Palmer S (1994) Fighting the big 'C': a guide for young people and their families to understanding cancer and it's treatment. CLIC, Bristol.

Parahoo K (1997) Nursing Research. Principles, process and issues (1st Ed) Macmillan Press Ltd, Basingstoke.

Peace G, O'keefe C, Faulkner A & Clark J (1992) Childhood cancer: Psychosocial needs, are they being met? Journal of Cancer Care 1 3-13.

Peace G, O'Keefe C & Faulkner A (1994) Whose role is it anyway? The role of general practitioners and the primary health care team in childhood cancer. Child Health. 1(6) 239-243.

Perrin J (1985) Special problems of chronic childhood illness in rural areas. In Hobbs N & Perrin J Issues in the care of children with chronic illness Jossey-Bass Inc., San Francisco.

Price S (1994) The special needs of children. Journal of Advanced Nursing. 20. 227-232.

Procter S, Campbell S, Biott C, Edward S, Redpath N & Moran M (1999) Preparation for the Developing Role of the Community Children's Nurse. English National Board for Nursing, Midwifery and Health Visiting, London.

Quine L & Pahl J (1989) Stress and Coping in Families Caring for a Child with a Severe Mental Handicap: a longitudinal study. University of Kent.

Quine L & Pahl J (1991) Stress and coping in mothers caring for a child with severe learning difficulties: a test of Lazarus' transaction model of coping. Journal of Community and Applied Social Psychology 1 57-70.

Quine L & Pahl J (1992) Growing up with severe learning difficulties: a longitudinal study of young people and their families, Journal of community and Applied Social Psychology 2 1-16.

Ramirez A, Addington-Hall J, Richards M (1998) ABC of palliative care. The carers. British Medical Journal 346 208-211.

Rees P, Tunstill A, Pope T, Kinnear D & Rees S (1989) Heart Children. Heart Line Association, Surrey.

Rigg K (1996) Personal communication Children's Hospice for the Eastern Region, Cambridge.

Roberton N (1993) Should we look after babies less than 800g? Archives of Disease in Childhood 68 326-329.

Robinson C & Jackson P (1999) Children's Hospices. A life line for families? National Children's Bureau, London.

Royal College of Nursing (1993a) Buying Paediatric Community Nursing. RCN, London.

Royal College of Nursing (1993b) Directory of Paediatric Community Nursing Services. 10th Edition. RCN. London.

Royal College Of Nursing, Paediatric Community Nurses' Forum (1994) Wise decisions Developing Paediatric Home Care teams. RCN, London.

Royal College of Nursing Paediatric Community Nurses Forum (1997) Annex 2 Children's Nursing Services. House of Commons (1997) Health Services for Children and Young People in the Community. Third Report of the Health Committee. Chair: Mrs Marion Roe. London: Stationery Office.

Sabbeth B & Leventhal J (1984) Marital adjustment to chronic childhood illness. A critique of the literature. Pediatrics 73 762-768.

Sainsbury C B Q, Gray O P, Cleary J, Davies M M, & Rowlandson P H (1986) Care by parents of their children in hospital. Archives of Disease in Childhood. 61. 612-615.

Sciarrillo W (1980) Using Hymovitch's Framework in the Family-Oriented Approach to Nursing Care. Maternal Child Nursing 5 242-248.

Shah R (1992) The Silent Majority: Children with Disabilities in Asian families. National Children's Bureau, London.

Sheridan M (1973) From birth to five years. Children's developmental progress. Routledge, London.

Sidey A (1995) Competence for community health care nursing (children). In Sines D (Ed) Community Health Care Nurisng. Blackwell Science, Oxford.

Siegel S (1956) Non-parametric statistics for the behavioural sciences. McGraw Hill, London.

Simons J (1994) Practical issues. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

Sloper P (1996) Needs and responses of parents following the diagnosis of childhood cancer. Child: Care, Health and Development 22 (3) 187-202.

Sloper P & Turner S (1991) Parental and professional views of the needs of families with as child with severe physical disability. Counselling Psychology Quarterly. 4(4). 323-330.

Sloper P Turner S (1992) Service needs of families of children with severe physical disability. Child: Care, Health and Development 18 259-282.

Sloper P Turner S (1993) Determinants of parental satisfaction with disclosure of disability. Developmental Medicine and Child Neurology 35 816-825.

Smith K (1989) Non-governmental organisations in the health field: Collaboration, integration and contrasting aims. Social Science and Medicine. 29(3). 395-402.

Smyth M & Robus N (1989) OPCS Surveys of disability in Great Britain. The financial circumstances of families with disabled children living in private households. HMSO, London.

Soutter J, Bond S, Craft A (1993) A philosophy of care. Nursing Standard 7 (44) 21.

Soutter J, Bond S & Craft A (1994) Families of Misfortune. Department of Child Health and Centre for Health Services Research, The University, Newcastle upon Tyne.

Spinetta J J, & Deasey-Spinetta P (1981) Talking with children who have life-threatening diseases. In Spinetta J J & Deasy-Spinetta P C V (Eds) Living with Childhood Cancer. C V Mosby, St Louis.

Stallard P, Mastroyannopoulou K, Lewis M, Lenton S (1997) The siblings of children with life-threatening conditions. Child Psychology and Psychiatry Review 2 (1) 26-33.

Stein A & Forrest G C, Woolley H & Baum J D (1989) Life threatening illnesses and hospice care. Archives of Disease in Childhood 64 697-702.

Stein REK & Jessop DJ (1982) A non-categorical approach to chronic childhood illness. Public Health Reports 97 (4) 354-362.

Stein REK & Jessop DJ (1989) What diagnosis does not tell: the case for a non-categorical approach to chronic illness in childhood. Social Science and Medicine. 29(6). 769-778.

Stein A & Woolley H (1990) An evaluation of hospice care for children. In Baum J D, Dominica F & Woodward R N (Eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Stein A & Woolley H (1994) Caring for the carers. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

Stein REK (1996) To be or not to be ..... non-categorical. Journal of Developmental and Behavioural Pediatrics 17 (1) 36-37.

Stevens D & Owen M (1987) Hospices for children? (letter) British Medical Journal 294 1548.

Stewart D, Stein A, Forrest G & Clark D (1992) Psychosocial adjustment in siblings of children with chronic life-threatening illness: A research note, Journal of Child Psychology and Psychiatry 33 (4) 779-784.

Stiller CA (1994) Malignancies. In Pless I B (Ed) The Epidemiology of Childhood Disorders. Oxford University Press, Oxford.

Stiller CA, Allen MB & Eatock EM (1995) Childhood cancer in Britain: the national registry of childhood tumours and incidence rates 1978 – 1987 European Journal of Cancer 31A 2028-2034

Stower S (1992) Partnership caring. Journal of Clinical Nursing 1 67-72.

Sutherland R, Hearn J, Baum D & Elston S (1993) Definitions in paediatric palliative care. Health Trends. 25(4) 148-150.

Tatman M (1993) National Directory of Services Outside Hospital for Children with Life-Threatening Illnesses and Their Families. Institute of Child Health, London.

Tatman M A & Woodruffe C (1993) Paediatric home care in the UK. Archives of Disease in Childhood. 69(6). 677-680.

Tatman M A & Woodruffe C, Kelly PJ, & Harris RJ, (1992) Paediatric home care in Tower Hamlets: a working partnership with parents. Quality in Health Care 1, 98-103.

Thomas J (1994) Parents. In Hill L (Ed) Caring for Dying Children and their Families. Chapman & Hall London.

Thompson M (1998) Children's Hospices: 15 years on. Paediatric Nursing 10 (5) 24.

Thornes R (1990) Towards a comprehensive system of caring for dying children and their families: Key issues. In Baum J D, Sr. Dominica F & Woodward R N (eds) Listen, My Child Has Got a Lot Of Living To Do. Oxford University Press, Oxford.

Trapp A (1994) Support for the family. In Goldman A (Ed) Care of the Dying Child. Oxford University Press, Oxford.

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1994) The future of professional practice. The council's standards for education and practice following registration. UKCC, London.

United Nations (1991) Convention on the Rights of the Child. HMSO, London.

Valentine F (1998) Empowerment: family-centred care. Paediatric Nursing 10(1) 24-27.

Van Dongen-Melman JEWM, & Sanders-Woudstra JAR (1986) Psychological aspects of childhood cancer: A review of the literature. Journal of Child Psychology and Psychiatry. 27(2). 145-171.

Vaz T (1995) Personal health records for school children with multiple needs. Child: Care, Health and Development 21 (3) 191-198.

Vickers DW, Maynard L, Ewan PW (1997) Management of children with potential anaphylactic reactions in the community: a training package and proposal for good practice. Clinical & Experimental Allergy 27 898-903.

Voysey M (1975) A constant Burden. Routledge/Kegan Paul, London.

Wallace A & Jackson S (1995) Establishing a district palliative care team for children. Child: Care, Health and Development 21 (6) 383-385.

Wallender J, Varni J, Babani L, Banis H, Wilcox K (1989a) Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. Journal of Pediatric Psychology 14 (2) 157-173.

Wallander JL, Varni JW, Babani L, DeHaan CB, Wilcox KT, & Banis HT (1989b) The social environment and the adaptation of mothers of physically handicapped children. Journal of Pediatric Psychology 14 (3) 371-387.

While AE (1989) The needs of dying children and their families. Health Visitor. 62(6) 176-178.

While AE (1991) An evaluation of a paediatric home care scheme. Journal of Advanced Nursing 16 1413-1421.

While AE (1992) Consumer view of health care: a comparison of hospital and home care. Child: care, health and development. 18, 107-116.

While AE, Citrone C & Cornish J (1996a) A study of the Needs and Provisions for families caring for children with life-limiting incurable disorders. Department of Nursing Studies, King's College, London.

While AE, Citrone C & Cornish J (1996b) Bereaved Parents' views of caring for a child with a life-limiting Incurable disorder. Department of Nursing Studies, King's College, London.

While AE & Dyson E Characteristics of Paediatric Home care Provision: the two dominant models in England. Child: Care, Health and Development. In Press.

Whitehead B, Helms P & Goodwin M (1991) Heart-lung transplantation for CF. Archives of Disease in Childhood 66 1018-1021.

Whiting M (1988) Community paediatric nursing in England in 1988. Unpublished MSc dissertation Royal College of Nursing, London.

Whiting M (1989) Issues in community care. In Bryczynska G (Ed) Ethics in Paediatric Nursing Chapman & Hall, London.

Whyte D (1992) A family nursing approach to the care of a child with a chronic illness. Journal of Advanced Nursing 17 317-327.

Whyte D, Barton M, Lamb A, Magennis C, Mallinson A, Marshall L, Oliver R, Reid P, Richardson H, Walford C (1998) Clinical effectiveness in community children's nursing. Clinical Effectiveness in Nursing 2 139-144.

Williams P (1997) Siblings and pediatric chronic illness: a review of the literature. International Journal of Nursing Studies 34 (4) 312-323.

Winter A & Teare J (1997) Construction and application of paediatric community nursing services Journal of Child Health Care 1 (1) 24-29.

Wise G (1994) The changing family. In Lindsay B (Ed) The child and family: contemporary nursing issues and child health and care. Bailliere Tindall, London.

Woolley H, Stein A, Forest GC, & Baum JD (1989a) Imparting the diagnosis of life threatening illness in children. British Medical Journal. 298(6688). 1623-1626.

Woolley H, Stein A, Forest GC, & Baum JD (1989b) Staff stress and job satisfaction at a children's hospice. Archives of Disease in Childhood. 64. 114-118.

Woolley H, Stein A, Forest GC, & Baum JD (1991) Cornerstone care for families with life-threatening illness. Developing Medicine and Child Neurology. 33 216-224.

World Health Organisation (1975) International classification of diseases (9th revision). WHO, Geneva.

Wray J (1996) Congenital heart disease and cardiac surgery: psychological implications for child and family. Unpublished PhD thesis University of London.